ON THE HUMAN SIDE...
OF ILLNESS AND RESEARCH

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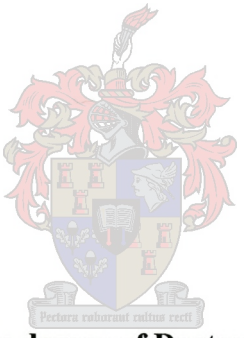

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Declaration

I, the undersigned, hereby declare that the work contained in this dissertation is my own original work and that I have not previously in its entirety or in part submitted it at any university for a degree.

Signature

Date

Abstract

This qualitative study comprised an in-depth investigation into the subjective – the explicitly human – experience of those suffering from Myalgic Encephalomyelitis (ME). I was, firstly, concerned with the nature and meaning of the social side of illness, that is, the sufferer's encounters with doctor, family member, friend and acquaintance alike. I was, secondly, set to develop greater insight into the essentially personal experience of being ill. I was able to conclude that, even amidst the inhumane presence of utter ignorance that permeate the very experience of ME, no ME sufferer is inevitably doomed a victim. They can always make a deliberate decision to have a say in their situation, in their own experience of their circumstances. They have the power of personal choice. Recommendations are, therefore, directed at expanding the potential extent and magnitude of this dynamic power.

The substantive focus of my study was enriched by a deliberate concern with the methodological implications of my own intimate involvement within the research process. I was here primarily concerned with my personal contribution to the research process as well as the influence thereof on the research relationships developed and the research strategies chosen and applied. I could not but conclude that the understanding I explicate is, as all social science theory, essentially a human construction, developed by me, in my distinctly human capacity. Recommendations are, therefore, geared to sensitise all social researchers to their own contribution to the construction of that which is eventually presented (and taken) as truthful knowledge.

In conclusion, I am thoroughly convinced that the experience of both illness and research is fundamentally human. This "humanness" cannot and should not be denied. Instead, I advocate a more deliberate focus on the human dimension of illness and research. Without such a focus, a more comprehensive understanding of either realm will continue to linger as but an elusive ideal.

Opsomming

Hierdie kwalitatiewe studie is gebaseer op 'n in-diepte ondersoek gerig op die subjektiewe – die onteenseglik menslike – ervaring van diegene wat ly aan Myaligië Enkefalomiëlitis (ME). Ek was, eerstens, geïnteresseerd in die aard en betekenis van die sosiale dimensie van siekte, dit wil sê, die lyer se ervaring van sosiale kontak met dokters, gesinslede, vriende en kennisse. Ek was, tweedens, gerig op die ontwikkeling van 'n grondige insig in die uiters persoonlike ervaring van siek-wees. Ek het tot die gevolgtrekking gekom dat, selfs te midde van die onmenslike teenwoordigheid van blatante onkunde wat die ganse ervaring van ME kenmerk, geen ME lyer noodwendig tot 'n slagoffer-status gedoem is nie. Hulle kan altyd 'n doelbewuste besluit neem om 'n sê te hê in hul eie situasie, in hul eie ervaring van hul omstandighede. Hulle het die mag van persoonlike keuse. Aanbevelings is dus daarop gerig om die potentiële trefwydte en impak van hierdie dinamiese mag uit te brei.

Die substantiewe dimensie van my studie is verryk deur 'n doelbewuste fokus op die metodologiese implikasies van my eie intieme betrokkenheid in die navorsingsproses. Ek was hoofsaaklik gemoeid met my persoonlike bydrae tot die navorsingsproses en die invloed daarvan op die ontwikkel van navorsingsverhoudings en die toepassing van gekose navorsingstrategieë. Hierdie fokus het gelei tot die besef dat die beskrywing wat ek aanbied, soos inderdaad alle sosiale teorie, essensieël 'n menslike konstruksie is, soos ontwikkel deur my, in my uitdruklik menslike kapasiteit. Aanbevelings is dus daarop gerig om alle sosiale navorsers te sensitiseer ten opsigte van hul eie bydrae tot die konstruksie van dit wat uiteindelik voorgestel (en geag) word as die waarheidsgetroue kennis.

In slotsom, is ek oortuig dat die ervaring van beide siekte en navorsing fundamenteel menslik is. Hierdie "mensheid" kan en behoort nie ontken te word nie. Inteendeel, ek bepleit 'n doelbewuste fokus op die menslike dimensie van siekte en navorsing. Sonder só 'n fokus sal 'n meer diepgaande begrip van iedere area bloot 'n onbereikbare ideaal bly.

Dedication

I dedicate this thesis to those ME sufferers without whom the present study would not have been possible as well as to all those ME sufferers who daily face, fail and conquer the experience of human illness and human suffering.

Acknowledgements

The financial assistance of the National Research Foundation (NRF) and the Deutscher Akademischer Austauschdienst (DAAD) towards the present research study is hereby acknowledged. Opinions expressed and conclusions arrived at are those of the author and are not necessarily to be attributed to either the National Research Foundation or the Deutscher Akademischer Austauschdienst.

I was furthermore fortunate to be the recipient of selfless hours by those who transmitted to me their knowledge of the subject under study. Without the insight offered by experts such as Dr Kobie Steyn these pages could scarcely have been written.

Sheer weight of numbers precludes my thanking all others, but I would be remiss if I did not acknowledge the contribution of the internal and external examiners for their useful comments on the work while in progress.

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Chapter 1
Introduction

It should be clear from the start: this study is all about stories. So, it seems appropriate to start with one …

One lovely summer evening we joined a party of eight for dinner. The company was well educated and all but one involved at the university in one capacity or another. We were affably mingling and getting to know each other better, exchanging stories both trivial and profound. In response to one of the many questions around the table, I explained to the host that my research was about the deeply personal experiences of people who suffer from yuppie flu. Abruptly, the tranquil and serene mood of our company turned frenetic. Suddenly everyone around the table had something to say, to ask, to add.

"Don't I know of someone suffering from it?" "Aren't these people just tired?" "How do you know that they actually have yuppie flu?" "Are they really, really ill?" "Isn't it just depression?" "What? Are there actually official criteria for diagnosing this illness?" "But aren't people just pretending to be ill?" And, "Oh", interjected the host quite authoritatively, "I heard it was just a terrible bout of diarrhoea".

Somewhere during the conversation one of the guests belatedly joined in. Not quite aware of the origin of this discussion, he assumed that because I was responding to all the questions, I must be the one with yuppie flu. And so he asked, quite innocently, "And you, do you use medication or is it just a matter of the right diet?" Anxiously, I struggled to think of a quick answer. What could I possibly say? Unexpectedly, and perhaps slightly ironically, the by now obviously ignorant host came to the rescue, explaining that it wasn't I who suffered from the disease; that it was merely the subject of my research. "Look", he even added, "she's in brilliantly good health; of course she's not ill".

And there I sat, dumb-founded, stunned into silence.

This story, which so vividly illustrates the ignorance and misunderstanding that surround ME, introduces and supports the very purpose of this study.

A story about illness

This study is about the subjective experience of those who suffer from the illness that is often so cruelly dismissed as "yuppie flu". Actually, "yuppie flu" refers to an illness widely known as ME (Myalgic Encephalomyelitis) and in certain circles also as CFS (Chronic Fatigue Syndrome).

It is an illness that, despite its broad incidence, is poorly understood, easily misconceived, and severely stigmatised. What is more, ME is an illness which inflicts serious incapacity and disability upon the sufferer. There is yet no cure. There is not even a sure way of treatment to soothe the symptoms and alleviate the disability. Medical practitioners appear to be as much in the dark about this illness as the sufferers themselves. With a medical solution thus seemingly a long way off, there is a dire need for a more immediate social solution to this illness.

A social solution demands greater understanding, recognition and support, both in medical circles as well as amongst the general public, that ME is a very real illness. Many ME sufferers feel that such understanding is of far greater importance than endless scientific debates about the aetiology and pathology of ME. These debates do not help them to cope on a daily basis. These debates do not help their family and friends to understand the illness any better. These debates do not even help their medical practitioners to treat them more efficiently. To ME sufferers these debates are, indeed, of very little (if any) use as they struggle through their immediate experience of pain and fatigue. This is clearly evident from sufferers' frustration with "always (being) treated like a collection of atoms instead of real, thinking, and feeling human beings" (Hennessy 1999). They are *human* beings with *human* needs reaching far beyond the simple (and currently often wholly inadequate) address of their physical disorder. It follows, then, that this study is specifically geared towards reaching a better understanding of the *human* suffering involved in the experience of ME. I earnestly wish that once this has been achieved, this understanding could be brought to the attention not only of the social science community, but even more importantly, to the attention of society itself.

To develop such a forceful understanding of the illness experience of those who have ME, I depended on the assistance of a selection of ME sufferers who were willing to share their experience of illness. These ME sufferers told me their stories about what it is like for them to have ME; about the ways in which this illness shapes their situations, their relationships and

their actions. And they told me about the meanings they give to the experience of living their lives with ME. Through the stories so constructed through our conversations, I wanted their voices – the voices of ME sufferers – to be heard.

A story about the research(er)

The story with which I introduced this study also accentuates the fact that I too have this illness, this "yuppie flu", this ME.

What does this mean for this study: what does it mean when the chosen research field hits so close to home? To find an answer to this question is exactly where the methodological focus of the present study comes into play. In other words, given my undeniable involvement in the field of ME, in the very experience thereof, what was my experience of the research? Did I find that I had expected too much of myself to become involved in a study that lay so close to my own being? Did I find that my own involvement, far from closing my research eyes, opened them to new possibilities? What did I find?

The remainder of the document will hint at and introduce possible answers to these questions. But there is one more thing to be said and done before I can proceed. In following the advice of Pollio et al. (1997: 48) in this matter, I now explain, at least as a prelude to the study, "my stake" in the research I had undertaken.

My stake is my illness, and my illness is now eight years old. It started while I was, like any other teenager, living a vibrantly active life filled with school, sport and friends. Yet, by the end of my third year at high school, my life had deteriorated to… well, to something that could hardly be called a life at all. I was most of the time unable to attend school, I could not enjoy participation in any kind of sport, and I hardly had any energy to spend with my family, let alone with my friends. During this stage, I found it difficult to do just about anything, brushing my teeth, combing my hair, getting dressed, everything seemed to demand so much energy. It felt as though I was completely and utterly depleted of all energy. It seemed that this drastic change was caused by a bout of infectious mononucleosis from which I just did not seem to recover.

Since falling ill I have had my share of good days and bad days. Indeed, my illness has gone through many ups and downs. During relapses, the sensation of acute illness still haunts me in the form of intense exhaustion, crippling muscular pains and weakness, problems with concentration and memory, and those pounding headaches. These features not only played havoc with the latter part of my high school career, but also turned my tertiary academic years into an arduous affair. For me, each relapse seemed to have been provoked by a variety of different factors, factors that I find difficult to single out and clarify. Some were related to mental, emotional or physical exertion; others simply to a pleasant outing which turned out to be just too much to bear. For me, these factors remain a closely interwoven mystery that has thus far proven too difficult to untangle and make sense of. In contrast to those grim patches of serious illness I, of course, also enjoyed better times during which I seemed to be gradually improving. Generally I am indeed quite a lot better now than I was at times before. Yet, I still cannot attempt any form of exertion without suffering the often severe repercussions. And I still wake up every single morning feeling utterly unrefreshed, as though I have not slept at all for days, for months.

During the course of the illness, and especially since the commencement of this study, I have also become more aware of an array of often lurking feelings that are either a product of or have been exacerbated by the illness. These feelings include a kind of loneliness brought on by being ill for weeks on end, despair of ever getting well again, detesting my dependency upon others, feeling marginal to other people's lives, loss at inevitably having to give up so much, and distress about people who have disappeared out of my life, even those that could have been friends. I became aware of, and had to face the negative and often intensely painful feelings the illness has wrought in my life.

These new perceptions changed me, my sense of Self, my perspective on life itself – but getting in touch with who I am, with my own responses, reactions and feelings, has helped me to understand myself better. Because I am now aware of these issues, I can adjust them and adjust to them. Perhaps this new sense of control, of being responsible for myself, has made the illness even a little easier to bear. And perhaps it has re-ignited a ray hope which was so easily dimmed by the onset of such an overwhelmingly disruptive illness.

This account of my own stake is not an attempt to offer an early answer to the research question which led to this study. After all, why ask a question to which you already know the answer? Instead, my account of Self adds to the sense and direction of the research question; it

provides the context in which the question was asked and, thus, the direction from which to look for meaningful answers to it (cf. Gadamer in Maso 1995: 12-13). In short, it is only when I am clear about where I am looking from, that I can understand what to look for and know when I have found it.

What is more, explaining my own stake certainly is not an attempt to be or become a more "objective" researcher. Indeed, far from making me more objective, it represents a way of becoming more sensitive to my own experiences that have undoubtedly served to shape and mould my presence and influence throughout the research process (cf. Pollio et al. 1997: 48). In this sense, my account of Self represents a description of my own way of seeing, my own distinctly *human* (and therefore inevitably limited) way of looking at and coming to know the human world I chose to set my gaze upon. It is, after all, only when I am clear about the contribution of my Self that the human world under study can assert itself – in my eyes - in all its unique complexity.

Thus, through my account of Self, I recognise that my suffering from ME may have influenced my conduct of this research. This in turn means that the story I was eventually able to tell about this world of illness experience was directly related to my Self, to the researching I responsible for the study. Taken more broadly to apply within the realm of social science research, this recognition means that the stories we as social researchers construct about a particular world of human experience is as much a function of the ways in which we look at and interact with this world as it is of the world itself (cf. Morgan 1983a: 13).

Telling a story

In looking at and interacting with the human world being studied we operate from – and so almost inadvertently reveal – a particular way of defining and forming knowledge. Kvale (1996: 3-5) explains, at the hand of two metaphors, that researchers here tend to operate from one of two primary positions.

In the *metaphor of the miner* knowledge is seen as buried metal and the researcher as a miner who unearths the valuable metal. Some miners seek objective facts to be quantified; others seek nuggets of essential meaning. In both conceptions, knowledge is simply waiting to be uncovered, to be mined out of the participant's pure experiences, wholly uncontaminated and

unpolluted by any involvement of the miner. Once uncovered, the precious nuggets of knowledge are placed on a conveyor belt where it is transformed, though not changed in essence, from oral to written state. Once these nuggets reach the end of the transformation process, the objective facts and essential meanings that they contain are filtered out and extracted by means of various analytic techniques. Finally, they are moulded into their pure, definitive form, the final product of the mining process (Kvale 1996: 3-4).

The value of the miner's product lies in its purity. Here, the degree of purity is measured by the extent to which it corresponds to objective reality, the purest knowledge of all (Kvale 1996: 3-4). This suggests that the research product is valued most highly when the researcher has or is at least able to convincingly show that a nugget of knowledge has been produced in a wholly uncontaminated form and is now justifiably represented as a mirror image of objective reality. In other words, when the researcher as a miner produces a research account, he or she is not really telling a story at all. It is rather a question of reflecting in the pages of written research text the human world as it was "discovered" in as pure a form as possible.

In the *metaphor of the traveller* the researcher is portrayed as a traveller on a journey that leads to a tale to be told upon returning home. The traveller explores the many domains of the country, either as unknown territory or with maps pointing to specific sites of interest. As the traveller wanders through the landscape, he or she engages with the inhabitants of the world through which he travels, and through their conversations the inhabitants tell their own stories of their lived world. Here, then, the traveller engages in "conversation" in the original Latin meaning of the word as "wandering together with". What the traveller so hears and sees is described qualitatively as he or she reconstructs it. The meanings in the original stories are separated and unfolded through the traveller's own interpretations. And they are remoulded into a new story to be told upon the traveller's return to his or her home country (Kvale 1996: 4).

The value of the traveller's tale lies in the insight it brings. Through his or her relationship with the inhabitants of the world being studied, the researcher's own understandings are both challenged and changed. Upon the traveller's return home, he or she is then able to lead others to new understandings and insights that may similarly challenge their taken-for-granted assumptions about the country in which the traveller had wandered (Kvale 1996: 4). Thus, the travel report produced by the researcher as a traveller is a story that gives evidence of the insight that has been co-constructed between the researcher and the researched.

In the ways in which they understand, value and present knowledge, both of these metaphors show important similarities to established schools of thought. The metaphor of the miner illustrates a common understanding in modern social sciences, very much reminiscent of nineteenth-century positivism, of knowledge as "given". That is, knowledge is simply waiting there to be discovered by the competent researcher. Nothing is required but care not to contaminate this pure metal. The metaphor of the traveller, on the other hand, is free from the tatters and remnants of nineteenth-century positivism and constitutes a slightly more post-modern understanding of knowledge and knowledge formation. In accordance with this understanding, human knowledge is constructed through and within human interaction and relationship. What is required here, then, is the sensitive formation of a human relationship through which stories about human life and living can be told.

Despite its promise of uncovering precious nuggets of pure knowledge, the miner metaphor did not reflect my perception of knowledge and knowledge formation. Instead, it is the traveller metaphor, with its strong emphasis on the human element of relationship, which more closely captures my way of thinking about knowledge, research and research relationships. Thus, the metaphor of the traveller became my chosen approach: my way of looking at the world under study and telling my story about it. It also, in a sense, became my way of (re-) locating knowledge construction specifically, and social research in general, more firmly within the realm of human practice.

Following a story

For the benefit of those who wish to follow my journey into the little known world of the ME sufferer, I now present an outline of the road taken – a travel itinerary, so to speak – through which the reader will be able to easily keep track of my journey and even, where deemed necessary, to retrace my footsteps.

The following two Parts introduce and explore the existing body of relevant knowledge I consulted to familiarise myself with the world being studied. In Part I the world of ME as the biological disease and as the subjectively experienced illness is surveyed. In Part II those works which explore the researcher's own contribution to the research process are reviewed. It is here, in the pages of old and new literature, that the central themes of this study are inserted into a larger body of developing knowledge and theory.

Part III details the path taken towards understanding and so discloses a process careful and systematic methodological planning. It shows that this path was firmly guided by the aim to do justice to the human world being studied and to do so in a manner both appropriate and sensitive to its very nature.

What I learned through my journey into the little known country of ME is described in Part IV. In this section, I recount my conversations with the inhabitants of this human world: the ME sufferers themselves. I tell my story – my rendition – of this world of human suffering and endurance, of ignorance and triumph. And it is a wonderfully human story, full of twists and turns, heartache and celebration. Through it, you will come to know the human sufferers who every day face, fail, and conquer their illness. You will come to know *the human side of illness*.

Having presented my story of the world of ME I then, in Part V, reveal more about my own experiences of and within this little known country. Here, I give an account of the adventures, the failings and the victories that marked my research journey. I reflect upon how these served to shape the story I was able to tell. And I consider the value of my story as I lay it open to the scrutiny of others. In the process, I bear my Self so that you will come to know me – the researching human I – as I was involved throughout the course of this study. As you do so, you will come to know *the human side of research*.

In the last Chapter, I reveal the final leg of my journey – returning home. Here, as I near my home country, I reflect upon what had transpired through the course of my journey. Was my journey indeed a path to understanding? Am I able to give any indication of ways to better understand and deal with the human world I wandered? And can I give any advice to travellers still to follow? As I responded to these questions, I could not but acknowledge that my journey into the uniquely human world of illness and research indeed both challenged and changed me. Perhaps, then, if I tell it well, this journey will similarly touch your life.

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Introduction

"ME is a serious debilitating illness that disrupts families, destroys lives and has immeasurable cost to the economy. Those whose lives are affected by ME need the support and understanding of our global village" (Editor, M.E.A.S.A. News 1999: 1).

In order to contribute towards increased support for and understanding of ME sufferers this study will, as described in Chapter 1, focus on the subjective experience of those who suffer from this disease.

A comprehensive understanding of this experience demands a thorough background of the history and present status of ME. Hence, in Part II, I present an overview of the history and definition of ME as well as a detailed description of the nature of this disease. In addition, I will also reflect upon some of the most commonly held misconceptions surrounding ME. Against this background, I will then attempt to gain greater insight into the devastating impact of this disease upon the sufferer.

However, before commencing with this discussion, I would like to clarify the use of the name, "Myalgic Encephalomyelitis" (ME). Such a clarification is necessary in the light of the current lack of agreement concerning the proper terminology by which to refer to this disease (Acheson 1992: 154; Henderson & Shelokov 1992: 173).

In recent history, a number of names have been suggested to describe this illness. Some of the names used prior to the conception of the term "Myalgic Encephalomyelitis" (ME) include Iceland Disease, Akureyri's Disease and Epidemic Neuromyasthenia (Ramsay & Dowsett 1992: 83).

Acheson (1992: 154) argues that a term such as "Iceland Disease" has the clear disadvantage of not giving the lay person any idea of the nature of the disease. It is also incorrect on historical grounds because the Los Angeles outbreak described by Gilliam represents the original account of ME in medical literature. The same disadvantages (with the added difficulty of pronunciation) apply to "Akureyri's Disease".

Henderson and Shelokov (1992: 174) prefer the name "Epidemic Neuromyasthenia". However, Acheson (1992: 155) argues that the first term is misleading because it suggests that this disease is confined to epidemics. The second term, translated as "nerve-muscle-weakness", has little meaning and suggests a disorder of the muscle end-plate, which runs contrary to recent electromyographic evidence. The verbal similarity with "neurasthenia", which means psychoneurosis, is also particularly unfortunate.

Some of the names invented subsequent to the conception of ME include Post-viral Fatigue Syndrome, Chronic Fatigue Syndrome (CFS), and Chronic Fatigue and Immune Dysfunction Syndrome (CFIDS) (Ramsay & Dowsett 1992: 83).

Chronic Fatigue Syndrome, the most widely used among these terms, was first described in 1988 by Dr Holmes and his associates who developed a working definition for research purposes (Levine 1992: 198). However, this term places sole emphasis on "fatigue" – a condition that is not only immeasurable and largely indefinable, but is also associated with both normal daily life as well as with almost all chronic disease states. The emphasis on "fatigue" belittles those who study this serious debilitating illness as well as those who suffer from it (Hyde 1992a: x).

Hence, many patients suffering from this disease loathe the name "Chronic Fatigue Syndrome". "Fatigue" is totally inadequate to describe the experience of the illness, "trivialising the severity of ME in some patients and not always reflecting what may be for some sufferers a different and much more disabling symptom" (Macintyre 1998: 27). In addition, Macintyre (1998: 27) also notes that the term "Chronic Fatigue Syndrome" has induced a certain "psychologisation" of the illness, accompanied by a belief by some doctors that this is a disease of mainly psychiatric origin.

In contrast, Ramsay and Dowsett (1992: 83) argue that the term "Myalgic Encephalomyelitis" (ME) does not trivialise the clinical severity of this illness.

Acheson (1992: 155) explains that when this term was first introduced in 1956 as "Benign Myalgic Encephalomyelitis" it was hoped that it would emphasise the absence of mortality, the severe muscular pains, the evidence of parenchymal damage to the nervous system, and the presumed inflammatory nature of the disease.

Yet, this term has been criticised by some who argue that the disease is certainly not always benign, not invariably myalgic, and possibly never encephalomyelitic (Henderson and Shelokov 1992: 173).

However, Acheson (1992: 155) defends the term "Benign Myalgic Encephalomyelitis" with regard to all three meanings. Firstly, benignity is relative; "benign" is probably justified by the fact that there is no other recorded infective disease of the central nervous system without mortality. In addition, the pain in this disease, although not invariably present, appears to be devastating and is perhaps the feature that impresses itself most forcefully upon the observer. As far as the final meaning is concerned, Acheson (1992: 155) states that in the present state of ignorance, "encephalomyelitis" seems preferable because it conveys the suggestion that the disease is infective in origin, which is almost certainly the case.

In the light of these arguments, as well as in consideration of the fact that it is unlikely that an adequate term will be found until more conclusive evidence is available, I have decided to use the term "Myalgic Encephalomyelitis" (ME), thereby avoiding any contention concerning the benignity of the illness, while simultaneously acknowledging the severely debilitating nature of the disease.

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Chapter 2
What is ME?

In this chapter I present an overview of the history and definition of ME as well as a detailed description of the nature of this disease.

Historical perspective

Historical routes

The origins of ME are ancient. Hyde (1992c: 111) shows that a disease complex that may have been ME was described as early as 1900 B.C. although the origins of this text were considerably older. Much of the mythology of ME was incorporated into western medicine at the time of Hippocrates in the fourth century B.C. and later taken up by Galen in the second century A.D. According to Hyde (1992c: 111) Galen was in fact one of the first to suggest that the disease complex known today as ME was related to physical disease and not hysteria. This view was not heeded.

For most of the next 2000 years very few physicians believed that ME, or any other disease for that matter, had an infectious cause. Instead, the concept dating from early Egyptian mythology that any unexplained illness was simply due to the gods, or hysteria, never died out, but was simply clothed in the pseudoscientific terminology of the day, and persisted with little criticism for most of this period (Hyde 1992c: 111).

In 1881 this stance towards infectious disease was challenged by the first recorded epidemic of paralytic poliomyelitis. However, blind to the increasing information pointing to an infectious process as the cause for poliomyelitis, some physicians still insisted as late as 1901 that paralytic poliomyelitis was the result of a psychological predisposition (Hyde (1992c: 112-113). Even today there are still physicians who hold this view of ME.

Epidemic ME

It was not until a full-blown poliomyelitis epidemic swept California in the summer of 1934 that ME was actually recognised as a separate epidemic disease. During this poliomyelitis epidemic another and different type of epidemic occurred among the staff of the Los Angeles County General Hospital. While 1301 cases of paralytic poliomyelitis were treated in this hospital alone, a further 1198 cases were diagnosed as not having poliomyelitis. What did they have? It is quite probable, as both Hyde (1992c: 113) and Steincamp (1988: 17) argue, that many of these patients had indeed contracted ME.

The symptoms of this epidemic were those of ME. The patients developed relapsing muscle weakness, unusual pain syndromes, personality changes, and memory loss – all indeed typical ME symptoms. Many of the staff doctors, although still very young at the time, never returned to full employment, while the nurses in particular were all treated for hysteria (Hyde 1992c: 113). This first carefully recorded ME epidemic, which came to be called atypical poliomyelitis, was the first of no less than 52 recorded outbreaks of ME from various parts of the world up to the present time (Macintyre 1998: 11).

According to Steincamp's (1988: 17-19) review of these epidemics, several ME outbreaks, and in particular the 1984 epidemic at the Nevada resort town near Lake Tahoe, stimulated major medical breakthroughs into the nature of ME. It also inspired leading virologists and medical researchers, such as Dr Tobert Gallo, a co-discoverer of the AIDS virus, to become involved in the quest towards a greater understanding of this disabling disease.

Interestingly, many of these outbreaks were closely associated with an outbreak of paralytic poliomyelitis. This was indeed the case in the 1948-1949 epidemic in Iceland that started as a poliomyelitis epidemic but ended as a major ME epidemic involving 1116 patients. This pattern was repeated in various parts of the United States, in Australia and in South Africa (Acheson 1992: 132-139; Hyde 1992c: 114-115; Steincamp 1988: 17-19). There thus appears to be numerous events in history that point directly towards a constant poliomyelitis-ME association.

Sporadic ME

Since 1979 there has been a substantial (though poorly documented) increase in sporadic cases of ME amongst the general public. These increases compounded slowly until the late summer

of 1984 when it appeared, as Hyde et al. (1992: 29) explain, that a critical mass was reached and a veritable explosion of ME occurred. Contrary to what may have been commonly expected, the numbers of those falling ill with ME did not drop after this period but have instead continued to rise.

With reference to this sporadic form of ME, Hyde et al (1992: 29) and Levine (1992: 203) report that, in terms of age, race and sex, this illness has apparently been diagnosed more often in young white females than in any other group. It has a particularly wide age spectrum, being increasingly documented in the paediatric population as well as in patients above age 50, with females representing as many as 65-75% of all cases. Racial predisposition is, however, currently uncertain as there continues to be the possibility of referral bias.

With regard to socio-economic status, Levine (1992: 203) observes that many media articles, particularly in the popular press, state that ME is a disease primarily of people in the upper/middle socio-economic groups. Levine (1992: 203) however argues that the apparent predominance of patients in upper socio-economic strata is more a matter of referral patterns than incidence. In addition, Steincamp (1988: 4) also remarks that it is perhaps the better educated who, in the face of malaise and medical indifference, have the necessary resources to search for a more precise diagnosis for their mysterious illness.

Hyde et al. (1992: 29) have found a definite occupational bias with teachers, health care workers and social workers most significantly affected. In addition, they have also observed that, within the health profession, those who work in psychiatric institutions or are directly involved in nursing seem to be particularly singled out. In the teaching profession, teachers who work in schools for the disabled appear to be particularly at risk.

In this regard, it has been suggested that these individuals represent a group of high contact with a potentially ill public and are thus exposed to more infectious illnesses. Although this may be true, Hyde et al. (1992: 29) argue that these very groups also tend to keep their immunisations up to date because of their line of work. Thus a potential relationship between inoculations and some infectious diseases seem to be suggested. It has, for instance, been observed that there is an increased risk of poliomyelitis occurring after prophylactic inoculation against smallpox.

It thus appears as though the disease ME has been known to occur epidemically since the earliest of times and, more recently, also sporadically. In both these forms, ME has affected individuals across a broad spectrum of age, race, sex, class and profession.

Definitions of ME

The first attempt to systematise ME into a useful working definition was made in 1988 by Dr. Holmes, a United States Government researcher, and his team. In the absence of a diagnostic test for this illness, the 1988 definition (cf. Table 2.1) was based on a complex of potentially related symptoms and signs that tend to occur together (Holmes et al. in Hyde 1992b: 9).

Although this definition represented a worthy start, Hyde (1992b: 7) points out that the very basis of this definition was haunted by these researchers' belief that it was the Epstein-Barr virus which caused what they named the "Chronic Epstein-Barr Syndrome". Holmes et al. (in Hyde 1992b: 9) did, however, acknowledge that it was inappropriate to use a name for the perceived syndrome that implied a specific causal agent when consensus about such an agent was still lacking. Hence, these researchers proposed a new name: Chronic Fatigue Syndrome (CFS).

Table 2.1 The 1988 Holmes CFS working case definition (Holmes et al. in Hyde 1992b: 9-11)

The 1988 Holmes working case definition of CFS

A case of CFS must fulfil the following two major criteria:
New onset of persistent or relapsing debilitating fatigue or easy fatigability in a person who has no previous history of similar symptoms. This fatigue does no resolve with bed rest and is severe enough to reduce or impair average daily activity below 50% of the patient's pre-morbid activity level for a period of at least 6 months.

Other clinical conditions that may produce similar symptoms must be excluded by thorough evaluation based on history, physical examination and appropriate laboratory findings. These conditions include, among others, psychiatric disease and drug abuse.

In addition, a case of CFS must fulfil at least six of the following minor criteria as well as two physical findings (e.g. sore throat, fever and tender glands). If no physical findings are present a case must fulfil at least eight of these criteria:

1. Mild fever
2. Sore throat
3. Painful lymph nodes
4. Unexplained generalised muscle weakness
5. Muscle discomfort or myalgia
6. Prolonged post-exertional fatigue
7. Headaches of a new type, severity, or pattern
8. Joint pain without joint swelling or redness
9. Neuropsychological complaints (e.g. forgetfulness, confusion, inability to concentrate)
10. Sleep disturbances

A symptom included as a minor criterion must have begun at or after the onset of increased fatigability and must have persisted or recurred over a period of at least 6 months.

However, Hyde (1992b: 11-12) argues that through this name the particular group of researchers took one symptom of the disease – fatigue – and elevated it to an unrealistic importance. Yet, fatigue is neither specific, definable nor scientifically measurable. In addition, fatigue is not only a normal and a pathological feature of everyday life, but also an integral part of many illnesses. By making fatigue the primary characteristic of this disease, the authors necessitated the elimination of hundreds of other diseases. Hence, to truly follow the criteria set out by this definition probably makes ME the most expensive illness to investigate of any known disease (Hyde 1992b: 11).

In addition, making fatigue the flagship symptom of this disease clouds the fact that the majority of ME symptoms are indeed central nervous system symptoms. Interestingly, as Hyde (1992b: 12) observes, central nervous system dysfunction was not part of the Holmes definition.

Jason et al. (1997: 973-974) identified another problem with the Holmes case definition of ME, namely that it requires six to eight minor symptoms which involve many unexplained

somatic complaints. However, the requirement of such a high number of unexplained somatic complaints can inadvertently lead to a selection of individuals with psychiatric problems. Hence, the use of this definition in research has produced erroneous estimates of the extent of ME co-morbidity with psychiatric disorders. Such estimates have led some to conclude that ME is purely a psychiatric disorder. The criteria prescribed by the original case definition, therefore, introduced an unfortunate bias into the realm of ME research.

In addition to these problems, researchers have applied the 1988 working case definition inconsistently. In practice, this case definition has indeed been frequently modified, especially since some of the criteria are difficult to interpret while others are difficult to comply with. In addition, opinions also differ with regard to the classification of chronic fatigue cases preceded by a history of psychiatric illnesses (Fukuda et al. 1994: 954).

Partly in response to the problems associated with the Holmes case definition of ME, the Oxford Guidelines, as presented in Table 2.2, were developed in 1991 by a British group of clinical and scientific researchers chaired by Dr Sharpe. This paper represents a further attempt to develop consensus on a case definition of ME as well as the methods of assessment to be employed (Hyde 1992b: 12-17).

Table 2.2: The 1991 Oxford Guidelines
(Sharpe et al. in Hyde 1992b: 12-17)

The 1991 Oxford Guidelines

Chronic Fatigue Syndrome (CFS)

1. A syndrome characterised by fatigue as the principal symptom.
2. A syndrome of definite onset that is not life long.
3. The fatigue is severe, disabling, and affects physical and mental functioning.
4. The symptoms of fatigue should have been present for a minimum of six months during which it was present for more than 50% of the time.
5. Other symptoms may be present, particularly myalgia, mood and sleep disturbances.

Certain patients should be excluded from the definition. They include:

1. Patients with established medical conditions known to produce chronic fatigue.
2. Patients with a current diagnosis of schizophrenia, manic-depressive illness,

substance abuse, eating disorder or proven organic brain disease. Other psychiatric disorders (including depression, anxiety disorders, and hyperventilation syndrome) are not necessarily reasons for exclusion.

Post-Infectious Fatigue Syndrome (PIFS)

As a subtype of CFS, the patient should fulfil the criteria specified for CFS as defined above. The patient should also fulfil the following criteria:

1. There is definite evidence of infection at onset or presentation.
2. The syndrome is present for a minimum of six months after onset of infection.
3. The infection has been corroborated by laboratory evidence.

Hyde (1992b: 18) however comments that the Oxford Guidelines appear to serve the single purpose of introducing the term "Post-infectious Fatigue Syndrome" as an acceptable term under which to publish. In this way the authors of this paper merely added confusion to the already overly complicated definition proposed by Holmes et al in 1988.

This view is supported by Macintyre (1998: 91-92) who points out that the Oxford Guidelines for ME do not require the person diagnosed with ME to suffer from abnormal muscle fatigue or pain, to experience fatigue made worse by exercise, or to have symptoms that vary from day to day. Yet, the Oxford Guidelines can include people with fatigue due to depression or stress caused, for instance, by "burn-out" from overwork. The Oxford Guidelines indeed added to the confusion surrounding ME.

Thus, because of the problems experienced with the case definition of ME as proposed by Holmes et al., as well as by the Oxford group, a need arose for revised criteria to define ME more clearly. Hence, in 1994, Drs Fukuda and others (Fukuda et al. 1994: 953-959) published a refined and modified working case definition of what they referred to as CFS. This definition is summarised in Table 2.3.

Table 2.3: The 1994 Fukuda CFS working case definition (Fukuda et al. 1994: 956)

The 1994 Fukuda working case definition of CFS

A case of CFS must fulfil the following major criteria:

1. Unexplained, persistent, or relapsing chronic fatigue that is of a new or definite onset (not lifelong).
2. Fatigue is not due to ongoing exertion.
3. Fatigue is not substantially alleviated by rest.
4. The fatigue results in substantial reduction in occupational, educational, social or personal activities.

A case of CFS must fulfil four or more of the following minor criteria:

1. Self-reported impairment in short-term memory or concentration severe enough to cause substantial reduction in occupational, educational, social or personal activities.
2. Sore throat.
3. Tender lymph nodes.
4. Muscle pain.
5. Multi-joint pain without joint swelling or redness.
6. Headaches of a new type, pattern or severity.
7. Unrefreshing sleep
8. Post-exertional malaise lasting more than 24 hours.

Each minor criterion must have persisted or recurred during six or more consecutive months of illness and must not have predated the fatigue.

The 1994 case definition clearly discarded all physical signs as major inclusion criteria. Fukuda et al. (1994: 957) explained that this exclusion was based on the fact that the presence of such signs had been unreliably documented in the past. In addition, the required number of symptoms was decreased from eight to four and the list of symptoms was reduced from eleven to eight. Fukuda et al. (1994: 957) remarked that, in modifying the 1988 criteria, the decision to retain any symptom criteria other than chronic fatigue generated the most disagreement among the authors.

This disagreement occurred between those who favoured a more restrictive approach (using several symptom criteria) as was done in the 1988 ME working case definition, and those who favoured a broader definition of ME (using fewer symptom criteria). Those favouring a more restrictive approach argued that the use of multiple symptom criteria best reflected the clinical sense of ME as a distinct entity. The other side argued that no symptoms have been shown to be specific for ME and that some studies suggested that a requirement for multiple symptoms biased the selection of cases toward those with psychiatric disorders. Disagreement over this particular issue underscored the need to establish specific features of ME and thus the need for further in-depth research into this illness (Fukuda 1994: 957).

A further very important difference between the ME criteria of 1988 and 1994 highlighted by Macintyre (1998: 92) is that minor psychiatric disorders – anxiety, non-psychotic depression and somatization – are not excluded when diagnosing ME. The resulting major differences in the description of the illness imply that studies of ME patients who were diagnosed at the hand of either the Oxford Guidelines or the 1994 Fukuda Criteria may include people who have various psychosocial or psychiatric reasons for being very fatigued.

In this regard, Fukuda et al. (1994: 957) defend their decision not to use specific psychiatric disorders as a basis for exclusion by pointing out that psychiatric conditions tend to be highly prevalent in persons with chronic fatigue and chronic fatigue syndrome. The exclusion of persons with these conditions would substantially hinder efforts to clarify the role of psychiatric disorders in fatiguing illnesses. Nevertheless, Jason et al. (1997: 976-977) emphasise that it remains crucial to ensure that those patients with solely a psychiatric disorder are not erroneously included within the ME rubric. Such inclusion will, after all, seriously complicate the interpretation of epidemiological and treatment studies.

Although they are of considerable importance, the guidelines contained in each of the above case definitions should be regarded as strictly tentative. It remains necessary to acknowledge, as Fukuda et al. (1994: 957) as well as Hyde (1992b: 18) clearly do, that until there is a better understanding of the aetiology and pathophysiology of ME, a perfect definition of this complex disease will elude even the most knowledgeable.

What is ME?

Theories concerning the aetiology and pathophysiology of ME abound (e.g., Cowley et al. 1990: 62-70; Levine 2000: 4-8; Steyn 1993: 1-6). One such theory implies the involvement of the central nervous system as the primary culprit. As this theory is the most prominent and apparently the most accepted of the available array of existing explanations (cf. Wessely et al. 1998: 239-242), it is the one that will henceforth be considered.

ME as a dysfunction of the central nervous system

According to Hyde (1992b: 18), the majority of symptoms given in each of the definitions discussed above strongly point towards the central nervous system as the primary system involved in ME. This is supported by Chabursky et al.'s (1992: 19-20) assertion that ME represents a major acquired central nervous system dysfunction in which the brain function undergoes a metabolic alteration. This persisting multi-level central nervous system dysfunction defines the nature of the disease and the disease process.

Hyde and Jain (1992: 38-39) explained this more clearly by stating that ME represents an acutely acquired, chronic change in the ability of the central nervous system to process, with any dependability, the functions of reception, interpretation, storage and recovery of information and to programme dependable, normal, smooth end-organ responses. Depending upon the patient, a physiological encephalopathy exists in one, but usually several, of the cortical areas responsible for motor, sensory, cognitive and emotional function. Those deeper levels of central nervous system function that are responsible for the co-ordination of motor, sensory, cognitive, emotional and hormonal functions and at times for rational value judgement may also be physiologically injured.

In particular, Hyde & Jain (1992: 38-39) are of the opinion that there is evidence of subcortical injury to the hypothalamic-pituitary-end organ axis and also to the limbic system, as that area is responsible for the co-ordination of so many central nervous system functions. This view is largely endorsed by Goldstein (1992: 400-402).

Causes of ME

According to Hyde and Jain (1992: 63) the dysfunction of the central nervous system, as explained above, may result from a chronic viral infection. Hyde (1992a: xi) propose that such

infection may provoke reactive changes in neuropeptide messengers which, in turn, stimulate compensating immune reactions to rid the body of this infectious stressor and to return the body to normal homeostasis. By definition, chronic infections have however managed to escape these initial compensatory immune mechanisms. Yet, the neurochemical homeostatic events continue to be employed uselessly and to the detriment of the organism.

Such chronic infection, which defies the protection offered by the immune system, has been linked to two theories of viral cause.

The first of these concerns the retrovirus concept. In this respect Hyde (1992a: xi) refers to the work of Dr Paul Cheney who believes that ME represents a new disease process caused by the emergence of an entirely new retroviral infection. Hyde (1992a: xi) suggests that this view should be taken seriously for, if Dr Cheney is correct, the new retrovirus may be pivotal to the understanding of the disease.

The second theory of viral cause, which is considered by both Edwards (1992: 223) and Hyde (1992c: 113-115), revolves around the enterovirus concept. This theory specifically concerns the possible link between ME and the poliomyelitis-enterovirus family. Hyde (1992c: 113) argues that up until 1956, when general poliomyelitis immunisation was introduced, many if not most of the ME epidemics occurred concurrently with or followed just after epidemics of paralytic poliomyelitis. Yet, after the introduction of immunisation, paralytic poliomyelitis virtually stopped, but ME persisted.

In addition, the introduction of poliomyelitis immunisation brought about a dramatic change in the nature of ME itself. Hyde (1992c: 114) explains that many patients who were affected by ME prior to 1956 suffered a paralytic association along with the typical symptom picture of ME. Yet post-1956 ME patients have been spared overt paralysis.

It is also interesting to note that, although paralytic poliomyelitis has been around since 1881, post-polio syndrome only began to surface around 1979 and only received its name during the same period when ME catapulted into public attention. There is also no notable difference in the clinical picture between these two disease syndromes except that in post-polio syndrome there has been a clear observation of an earlier paralytic poliomyelitis illness. This leads Hyde (1992a: xii) to question how well physicians truly understand poliomyelitis, not to mention ME.

Thus, while either a retrovirus or an enterovirus may attack the central nervous system and so cause ME, further research is needed to substantiate these theories. Such research is also demanded because it is still not clearly known if a triggering disease, such as an infecting virus, is in fact the cause of ME, or if the triggering disease is a convenient non-specific destabilising virus that provides the ultimate injury to a pre-existing destabilised, overly stimulated immune system (Hyde et al. 1992: 27).

The apparently inadequate immune response to an infecting agent noted in ME sufferers by both Edwards (1992: 223) and Komaroff (1992: 232) hint at such a destabilised immune system. Such immunological disturbance, which allows the reactivation of latent or ineradicable infectious agents, particularly viruses, may contribute to the morbidity of ME – directly, by damaging certain tissue, and indirectly, by eliciting an on-going immunological response. In particular, the elaboration of various cytokines as part of this on-going immunological war may produce various ME symptoms such as fatigue, myalgia and fever (Jones 1992: 269; Komaroff 1992: 232).

It is, however, still unclear what triggers such immune dysfunction in the first place. Komaroff (1992: 232) suggests that many factors could do so on both the central and the peripheral level of immune function. Such factors may, for instance, include exogenous infectious agents, environmental toxins, stress, emotional strain, or even the biology of an underlying affective disorder (cf. Ader et al. 1995: 100-101; Esterling et al. 1994: 291-297; O'Leary 1990: 366-371). Komaroff (1992: 232) concludes that it is extremely unlikely that any single explanation will serve to adequately define this extremely complex illness.

The complexity of ME has undoubtedly contributed towards the current unsatisfactory state of knowledge of the exact causal agents involved in the illness. Although available data permit many interpretations, it provides strong support for none (Komaroff 1992: 232). Hence, the true aetiology and pathophysiology of ME remains a mystery despite the intensive efforts by competent researchers in a number of different fields.

ME symptoms

Hyde and Jain (1992: 42-43) clearly state that central nervous system dysfunction and, in particular, inconsistent central nervous system dysfunction is undoubtedly the chief cause of both mental and physical disability in ME.

The symptoms commonly associated with such disability are briefly reviewed below in random order. This review will provide a useful background against which a thorough understanding can be developed of the experience of those who suffer from this disease.

Fatigue

Fatigue is a universal daily life experience and has probably evolved as a safety mechanism to force humans to rest at the right times. At times the sensation of fatigue is therefore appropriate and does not necessarily indicate illness. In the case of ME it is the nature of the fatigue and the post-exertional feeling of illness, accompanied by the rapid onset of brain fatigue, that differentiates it from the symptom of "feeling tired all the time". The majority of people with ME do not, in fact, feel fatigued "all the time"; sometimes they may even feel as though they have normal energy, but their energy simply runs out very quickly (Macintyre 1998: 30-31).

It is thus clear that the nature of the fatigue experienced by ME sufferers has both physical and mental dimensions. Lane (1992: 395-396) observes that patients may try to distinguish these dimensions by reporting physical fatigue as tiredness, lack of strength, and inability to perform physically at their previous level (or at what they perceive that level to have been), while mental fatigue may be described as vague drowsiness and disinterest.

It is also clear that fatigability and post-exertional fatigue represent very prominent features of ME. Hence, patients may complain that mental or physical activity increases their fatigue disproportionately and indeed exerts a "cost" in terms of an exacerbation of the symptoms associated with ME (Lane 1992: 396).

Macintyre (1998: 145-146) explains that it seems to be specifically the concept of "post-exertional fatigue" that is generally very poorly understood. There appears to be confusion between the fatigue felt by a normal person after a game of tennis and that felt by someone with ME after minor exercise. The former is described as "healthy tiredness"; it refreshes the mind, improves appetite and leads to a good night's sleep. The muscles may ache, but this is generally relieved by a hot bath and sleep. In contrast, the post-exertional fatigue typical of ME needs to be experienced to be understood. It is not just tiredness - it is feeling horribly ill, collapsed as though poisoned, with visible muscle twitching, intense pains in the muscles and

maybe in the joints, nausea, sweating, insomnia and nightmares, maybe elevated temperature and recurrence of sore throat and tender, enlarged glands. This fatigue (which word is an understatement of the condition) is certainly not relieved by a good night's sleep.

Pain syndromes

Pain syndromes in ME can vary from totally disabling, to occurring only after exercise, to non-existent. When they do occur, and that is in over 60% of ME patients, the variety of pain syndromes can be legion. Hyde and Jain (1992: 58) explain that the very number of them can cause grave anxiety to the patient and help create scepticism on the part of the physician who may believe that no one in their right mind could have this many symptoms. Physicians have been trained to associate pain with local or referred pathology and, hence, almost never associate or ascribe pain as a central dysfunction. Once they have scrupulously investigated pain for its possible cardiac, surgical or malignant origins they tend to feel impugned if their search reveals no local pathology. They then tend to blame the patient for the pain syndrome by terming it hysteria or somatization (see Chapter 3). However, it is more likely that the majority of these pain syndromes are manifestations of central pain receptor deregulation or injury.

One of the most important ME pain syndromes identified by Hyde and Jain (1992: 58) is malaise. Malaise is accentuated in the initial stage and it recurs for as long as the disease process exists. Malaise is almost impossible to describe. It is often described as the pain and discomfort that one has during the acute phase of influenza although it is not always the same. The patient feels terrible, as though he/she is about to die. There is no fever as in influenza or dimming of consciousness that, mercifully, usually occurs in the malaise of a febrile influenza attack. The malaise tends to wander, to wax and wane. It particularly injures the sensory and dulls the cognitive abilities of the brain. During such attacks the rapid muscle and brain fatigue that is normal in ME becomes accentuated.

This malaise is often exaggerated or cumulative in association with specific events. As a rule it occurs after any physical exercise that goes beyond the normal everyday work output. Malaise may occur often in place of what would have been an infectious illness. Many patients will thus inform the physician that since they fell ill with ME they have never once had a typical cold or external sign of an upper respiratory infection. Instead, they most likely have had many "crashes" (Hyde & Jain 1992: 58).

According to Hyde and Jain (1992: 59) another very common pain syndrome closely associated with ME involves dull, persistent, moderate to severe bilateral pain in the area "behind the eyes". Patients sometimes describe this pain as a feeling of having been clubbed. ME patients may sometimes also experience a total head pain that can be described as feeling "as though one's head was expanding and blowing up".

A further common pain syndrome, which has given rise to the common French name for ME, "Spasmophilie", involves muscle spasm. Localised spasmodic or tetanic muscle spasm is very common is the illness. Both single muscle and muscle groups may be involved (Hyde & Jain 1992: 60).

Hyde and Jain (1992: 61) furthermore also observe that the most common abdominal pain occurs in the lower abdomen and particularly in the urogenital system. This symptom is definitely worse in post-pubertal females, who may suffer excruciating pain that is often associated with any and every form of menstrual irregularity and cessation. Within this pain syndrome the principle element is again most likely to be severe muscle spasm. The muscle sphincters are particularly prone to persistent pain of this type.

Hyde and Jain (1992: 62) identified muscle pain as a closely related pain syndrome central to ME. The patient may complain of feeling "as though he/she has been beaten with an axe handle". In other words, the patient feels bruised and hurt. This pain lingers for several hours and then departs, usually only after the patient has slept. It is sometimes associated with a dull generalised headache as well as increased inability to concentrate. At other times, the patient may experience severe pain in a main muscle mass feeling "as though a knife or arrow had been stuck into the muscle". Muscle pain may often be related to the use of a particular muscle group that goes beyond the normal everyday activity.

Cognitive dysfunction

Cognitive dysfunction is certainly one of the most disabling of the ME symptoms. "When this simple fact is understood, it becomes immediately apparent why this is such a devastating disease for children, students and adults" (Hyde & Jain 1992: 42). Patients can return to work or school with pain, with muscles spasm, with fatigue, with motor dysfunction, but when they have consistent difficulty in making new memories, recalling old memories and co-ordinating new and old information, they are of little use to the modern work force. "It is the combination

of the chronicity, the dysfunctions, the instability, and the lack of dependability of these dysfunctions, that creates 'the most chronic of chronic disabilities'" (Hyde & Jain 1992: 43).

Some of the neurological dysfunctions of ME, as highlighted by Hyde and Jain (1992: 43-45) as well as by Macintyre (1998: 6-9, 22-23), include loss of verbal and performance intelligence quotient, dysfunction in simultaneous processing, receptive and expressive dysphasia, reading comprehension dysfunction, and dyscalculia.

Loss of verbal and performance intelligence quotient

Admission of a significant verbal and performance I.Q. loss represents a threat to sufferers' work and social abilities as well as to their own sense of identity. This may be particularly significant in the light of recent research findings, cited by Hyde and Jain (1992: 43), which estimate that the average ME patient may lose approximately 20% of his/her estimated pre-illness I.Q.

Bastien (1992: 459) found that while most of the patients included in her study were high functioning and successful individuals prior to their illness, they now had I.Q. scores in the average range. Performance I.Q. is significantly lower than Verbal I.Q. in most of these patients, probably indicating greater right hemisphere dysfunction.

Dysfunction in simultaneous processing

Early in the disease process patients may be distracted and unable to concentrate, simply because of the severe headaches that are frequently associated with the onset. Others have "noise" in their head that is often described as buzzing, or the crackling and hissing of a short-wave receiver slightly off the frequency channel. The symptom storms, the myalgias, and the anxieties also make it difficult to concentrate. However, as Hyde and Jain (1992: 43-44) explain, there comes a period in the disease process when these symptom storms settle down and the patient becomes acquainted with his or her new internal environment. When that occurs, primary lack of concentration becomes obvious.

Within this context, an ME patient may understand a single person speaking directly to him or her, but may be quite unable to understand the same conversation from the same person when it occurs telephonically. In the latter instance, the patient experiences more difficulty in concentrating and following the conversation than in a face-to-face conversation. Visual and

multi-sensorial cues, therefore, appear to be very important to ME sufferers (Hyde & Jain 1992: 44).

Hyde and Jain (1992: 44) also explain that an ME patient may have no difficulty at a dinner party with two or three persons and one table conversation, yet, with multiple persons and conversations, the same patient may be unable to understand a word that is said. In addition, such a patient may not even be able to recall the guests and, in extreme cases, not even the dinner party itself the next day.

Hyde and Jain (1992: 44) illustrate the dysfunction in simultaneous processing by explaining that although an ME patient may have no difficulty or anxiety walking in the country, this same patient may experience panic in crowds and even more so in a busy shopping centre where he or she is deluged with multiple discordant sensory information.

While it is true that all individuals tend to concentrate better when the input of information is specific and simple, a normal individual has the ability to block out extraneous and unwanted information or noise. However, ME patients seem to lose the ability to distinguish noise from required information and tend to shut down all intake after simple fatigue sets in. Hyde and Jain (1992: 44) note that this receptive shutdown has alarming implications for making memories.

Receptive and expressive dysphasia

Closely allied to concentration is the difficulty in understanding speech and in speaking. Patients may complain that while they are able to hear spoken words clearly, the words make absolutely no sense to them. These patients have lost the ability to interpret normal language (Hyde & Jain 1992: 44).

In addition, Hyde and Jain (1992: 44) note that when ME patients speak, important elements may be left out of the sentence or the syntax may be askew. Patients are usually aware of these structural faults in their own conversation and at times become overly conscious of this.

Reading comprehension dysfunction

A patient who suffers from this dysfunction can still read, but can neither comprehend what is read nor compare it with known information that has previously been stored. This dysfunction

is one of the primary cognitive problems encountered by ME patients and it plays havoc with the patient's ability to perform tasks, let alone to learn new ones (Hyde & Jain 1992: 44).

In addition, this dysfunction is also closely related to sequencing dysfunction which adversely influences patients' ability, for instance, to look up telephone numbers in a telephone directory. This dysfunction is also illustrated by the confusion experienced by patients when attempting to make simple decisions (Hyde & Jain 1992: 44).

While these skills do tend to improve during the recuperation stage of the disease, Hyde and Jain (1994: 44) state that much may be lost.

Dyscalculia

Hyde and Jain (1992: 45) contend that perhaps the one overriding cognitive dysfunction observed in almost all ME patients, irrespective of their prior mathematical abilities, is the development of dyscalculia. Patients for instance have difficulty in or cannot make change or add up columns. ME patients frequently cannot remember telephone numbers very well. In addition, confusion with timetables is also common. Patients may, therefore, routinely show up at the wrong time or on the wrong day.

Auditory dysfunction

Many different forms of central auditory dysfunction are recognised in ME patients. According to Hyde and Jain (1992: 47) these include:

- An inability to comprehend in the presence of multiple auditory signals
- Loss of tone perception
- Discomfort, pain and "noise" associated with hearing a sound signal of even a modest decibel level
- A sudden loss of appreciated sound

Yet, perhaps the greatest hearing problem is associated with the difficulty and at times inability to interpret spoken or auditory information. This is confirmed by the results of Bastien's (1992: 455) study of ME patients which suggest serious left temporal lobe dysfunction that is directly associated with a decreased ability to process, encode, and retrieve auditory

information. According to Hyde and Jain (1992: 47) this dysfunction represents one of the most central problems of ME.

Visual dysfunction

ME patients will frequently complain of a sluggish or decreased range of accommodation, often compared to a slow zoom lens. Patients with previous normal accommodation will, with the onset of ME, relate that when changing focus from near to far objects, their accommodation adjustment is unusually slow to react. In addition, patients frequently complain of double or blurred vision, especially when tired. Patients also frequently suffer from a loss of night vision (Hyde & Jain 1992: 48-49).

Yet, the primary central visual dysfunction is equivalent to the auditory dysfunction mentioned above. The patient fails to integrate and store visual information in a meaningful way. Hyde and Jain (1992: 49-50) point to the following problems provoked by this particular dysfunction:

- Reading: Patients may temporarily lose their ability to easily comprehend what they read. For most patients, this disability occurs significantly during the first 6 months of the onset of ME. Their reading ability then improves to reach a new plateau, subjectively below their previous level (Hyde & Jain 1992: 49).

- Writing: To write, one must not only have the ability to recall, but also to read and comprehend what one has written. ME patients can make ridiculous spelling and grammar errors and may even fail to notice these omissions (Hyde & Jain 1992: 49-50).

- Distance and spacial dysfunction: The human brain interprets distance not only by parallax but by the complex ability to recall, associate and compare appropriate visual and visual memory cues. People's depth and speed perception work in tandem to interpret motion, speed, and vector. Hyde and Jain (1992: 50) correctly point out that these functions protect people as much in crossing a road as they protect a teacup when it is placed upon a shelf. The following problems related to these functions are generally reported by ME patients (Hyde & Jain 1992: 50):

- Jay walking: Patients cannot jay walk or cross streets in the absence of a traffic light due to the loss of the ability to judge speed, distance, deceleration and vector.
- Traffic motion: Patients, as drivers as well as passengers, experience an inability to judge the speed and position of cars approaching from the side.

Seizure activity

Hyde and Jain (1992: 51) are of the opinion that ME patients experience seizure activity. It is their observation that all seizure activity is greater in the initial stage (0-6 months) of ME and decreases considerably in the recuperation stage (2-12 months). In the chronic stages, occasional bursts of increased activity may persist. According to these authors, the most common seizure activity observed in ME patients is absence (petit mal) seizures. These seizures usually consist of simple episodes which normally last less than 10 seconds.

Hyde and Jain (1992: 52) proceed to distinguish between simple partial seizures and complex partial seizures.

Simple partial seizures, such as the following, may suggest important areas of central nervous system dysfunction (Hyde & Jain 1992: 52):

- Somatosensory seizures: The patient complains of tingling or pins and needles in the extremities and face.
- Autonomic seizures: During such seizures the patient experiences flushing of the face, a rise in blood pressure, sweating, dilatation and contraction of the pupils, and retardation of the respiratory rate.
- Focal motor seizures: This can involve involuntary movement of both a single muscle and/or muscle groups.
- Auditory seizures: The patient has ringing or hissing in the head and may also have associated pain.

Complex partial seizures, as listed below, tend to be episodic, very short-term and frequently have dramatic responses (Hyde & Jain 1992: 52):

- Olfactory hallucinations: The patient frequently complains of intense and unusual smells that are not apparent to others. This doubtlessly represents a limbic system derangement.

- Episodic dysphasia: The patient experiences episodic difficulty in maintaining volume of speech. The patient may have spasmodic difficulties of the larynx and upper oesophagus with or without activation by swallowing.

Hyde and Jain (1992: 53) furthermore also mention a number of uncategorised seizures:

- Tremulous attacks: The patient has subjective attacks of tremulousness. These may last up to one minute and are common even in chronic cases.
- Psychomotor attacks: The patient does not lose consciousness but may be confused and anxious.
- Episodic affective disorders: Abrupt changes in emotional response frequently triggered by fatigue or multiple sensory input barrages and may consist of inappropriate fear, anxiety, pleasure or happiness.

Sleep dysfunction

Hyde and Jain (1992: 54) clearly state that few if any ME patients in a full-blown state of the disease escape sleep dysfunction. During the initial stage in the disease process, the ME patient commonly suffers from hypersomnia. During this hypersomnia state the patient's sleep resembles that of normal sleep. While patients can always be aroused to some extent, they will usually tend to fall back to sleep as soon as they are left alone.

However, in contrast with the initial stage of the disease process, the recuperation and chronic stages of ME are characterised by insomnia as a primary central dysfunction. While the exact reasons underlying such insomnia are not yet clear, Hyde and Jain (1992: 54-56) mention a number of possible causes. These include night temperature variation, night extremity hypothermia, urine output, malodorous sweats, vivid and often frightening dreams, fear of dying due to the initial frightening symptom picture of ME, pain on movement, night headaches, hypersensitivity to sound and reactions to medication.

Hyde and Jain (1992: 56-57) furthermore also point to the occurrence of dream disorders. This is commonly characterised by a change in content, colour, and violence of the dreamscapes of ME patients. Patients will often mention the intense brightness and colour of their dreams, as well as the violence and the frequent aggressive nature of their dreams.

Emotional dysfunction

Macintyre's (1998: 80) discussion reveals that emotional disturbance is very common in patients with ME. Such disturbance may manifest itself in the form of emotional lability. Macintyre (1998: 176) explains that those ME patients who do suffer such emotional lability may experience black despair, non-stop weeping, and suicidal feelings for a few days, then wake up one morning feeling fine. On another day they may be irrationally happy, laughing and excited, perhaps about nothing more than waking up without pain. Unfortunately such euphoria usually leads to delusions of ability and too much activity, resulting in an exacerbation of symptoms, followed in turn by a state of sheer exhaustion and despondency.

Hyde and Jain (1992: 63) says that this abrupt change from a person with normal emotional control to one of pathological emotional dysfunction is noted in every epidemic and is indeed very common in sporadic cases. Such dysfunction is related to anatomical and physiological damage to certain centres of the brain that affect emotion control. Injuries to those areas of the brain that affect emotion are of the same nature as injuries to brain areas that affect physical function.

It is important to note that, besides the fact that ME tends to become chronic, there is also an unpredictable variation in the nature and severity of symptoms from week to week, day to day, even hour to hour (Macintyre 1998: 7).

According to Hyde et al. (1992: 26), the variable expression of the symptom pattern as indicated above can be explained by injury to different functional areas of the central nervous system. This symptom variability is quite comprehensible if one realises that ME, like paralytic poliomyelitis, can injure certain areas of the central nervous system while missing others. This, once again, points to the primary involvement of the central nervous system in the clinical presentation of ME.

The disease process of ME

The dysfunction of the central nervous system defines the entire disease process of ME (Hyde & Jain 1992: 42-43). This process, specifically where ME is marked by an acute onset, is arbitrarily divided by Hyde et al. (1992: 33-35) into four overlapping stages, namely the initial stage, the recuperation stage, the early chronic stage, and the late chronic stage.

The initial stage

During the initial stage, which may last up to six months, the illness frequently declares itself by a dramatic barrage of symptoms following one of several prodromal symptom pictures. There is usually a significant degree of malaise or total body discomfort such as one is likely to encounter in an acute attack of influenza. This malaise is accompanied by severe exhaustion and an alarming fluctuation and variability of symptoms (Hyde et al. 1992: 32-33).

Hyde et al. (1992: 32-33) also points to a tendency for these multiple symptoms and signs to come in "storms". In this initial stage, these storms seem to have a life of their own without any apparent triggering mechanism. In the recuperation and later stages, the storms may be provoked more clearly by unusual but not necessarily excessive activity or association with infectious disease.

In the light of the great number and inexplicable nature of these symptoms, patients also frequently suffer from severe anxiety or panic attacks (Hyde et al. 1992: 32-33).

The recuperation stage

The initial stage is followed by what Hyde et al. (1992: 33) call the recuperation stage which usually lasts between one and twelve months. This stage is characterised by a decrease in the number and severity of symptoms and symptom storms while there tends to be an uneven return of abilities. Some patients may recover most or all of their physical but not their cognitive abilities. Others again may recover their mental abilities but not their physical strengths. Those functions commonly associated with brain function, for instance memory, emotional control, reading comprehension, and sensory perception, will particularly vary according to the degree or completeness of recovery. According to Hyde et al. (1992: 33) this suggests an unequal level of damage, variable location of injury, and variable recovery of both mental and physical functions.

Such "recovery", irrespective of its variability, may however seduce some patients into thinking that they have completely recovered. Yet, on closer scrutiny many of these patients will have returned to work and social activity simply at a reduced level of mental and physical ability. Unfortunately, physicians who observe such "recovery" in one ME patient may tend to generalise this recovery into the expectation that all ME patients will recover and that those

who do not somehow have something psychologically (or worse yet, morally) wrong with them (Hyde et al. 1992: 33).

The early chronic stage

Hyde et al. (1992: 33-34) describes the next stage in the ME disease process as the early chronic stage which may persist from one to six years. This stage is characterised by utter exhaustion of muscle and central nervous system functions as the patient attempts to return to normal activity. The typical ME symptoms as described above still exist, perhaps in a more diffuse but not necessarily in a less disabling pattern. Hyde et al. (1992: 33) note that those ME cases which are marked by a more insidious onset have a clinical and symptom spectrum that resembles this early chronic stage.

During the early chronic stage most patients continue to show a very slow and uneven period of recovery and adaptation to the altered state of their central nervous system, muscle and social function. Some patients will adapt to their altered internal environmental circumstances while others will not be able to make this transition. However, the difference in those who adapt and those who do not is not simple. Hyde et al. (1992: 34) suggest that this process of rehabilitation may be influenced by a number of factors including the patient's pre-ME intellectual assets, the level and type of pre-ME education, the degree and area of central nervous system injury, the availability and quality of social and economic support facilities, and the patient's access to appropriate re-education programs.

Unfortunately, many patients in this stage of illness will not recover sufficiently to enjoy either work or social activities at the far higher level they enjoyed before, and thus may see their hopes and expectations shattered and destroyed. As a result, patients are most likely to commit suicide during this period (Hyde et al. 1992: 34).

The late chronic stage

The last stage in the ME disease process is the late chronic stage which lasts from six years onwards. During this stage it appears that patients who do not enjoy adequate recovery and support increasingly tend to become hermits (Hyde et al. 1992: 35).

It is these patients who tend to be forgotten. They have adjusted their lives to their altered abilities and may even show some minor improvements in function. Yet, according to Hyde

and his colleagues (1992: 35), this is largely due to their accepting their altered abilities. Physicians do not generally see these individuals since they have given up all hope that the medical profession can be of any service to them. Hence, these individuals tend no longer to be recognised as suffering from a very real and severely disabling disease.

Furthermore, despite their previous relatively high earning ability, many of these ME patients are likely to become impoverished, being left with no appreciable disability insurance (Hyde et al. 1992: 35). Ramsay and Dowsett's (1992: 83-84) study among 420 ME patients who have been ill for more than 10 years confirm this tragic economic outcome of ME. According to these authors, over 80% of professional and technical workers suffering from ME have been obliged to retire early or work only part time. The resulting loss in earnings is truly tremendous, not to mention the loss of skills and education to the work market.

Hyde et al. (1992: 35) observes that despite such dismal research findings this stage of the ME disease process is almost totally devoid of any significant research funding. Hence studies such as the ones mentioned above cannot be replicated and verified. As a result, the late chronic phase of ME will remain replete with all the mythologies that occur when scientific scrutiny is absent.

Treatment

Because of the large measure of variability inherent to the clinical presentation and course of ME, the treatment of this disease represents an extremely difficult task. This also explains why no specific treatment protocol for ME has been developed yet. Hence, professional assistance is largely directed at the relief of symptoms as well as at the reintegration of the patient into society at a level consistent with his or her illness (Vorster 1996: 19-20).

Goldstein (1990: 150-156), Steincamp (1988: 141-190) and Vorster (1996: 20) explain that the management of ME generally revolves around the conservation of the precious amount of energy available to the patient through abundant rest and sleep. This is usually balanced against a program of graded exercise, and supplemented by a healthy individualised diet that is likely to include vitamin and mineral supplements. This regime can also be enhanced through specific individualised symptomatic medical treatment. In addition, patients may also choose to manage their illness through less orthodox means including acupuncture, aromatherapy,

homeopathy, massage, naturopathy and reflexology as well as through meditation, relaxation and yoga techniques (Macintyre 1998: 193-285; Shepherd 1998: 252-296).

For many patients such an approach should be combined with individual or group psychotherapy (cf. Prins & Bleijenberg 1999: 325-339). Vorster (1996: 20-21) explains that psychotherapy can offer ME patients instruction in coping skills, direction in identifying important activity limits, and guidance during major life changes. Psychotherapy can thus facilitate adjustment to and acceptance of the illness, while simultaneously providing guidance towards improvement.

Yet, while psychotherapy may have a potentially important role to play within the context of ME and ME treatment, it cannot be seen as a cure for this illness. Its greatest value lies instead, as Vorster (1996: 21) concludes, in the effective management of ME.

In this section it has become clear that ME, as a disease of the central nervous system, has an uncertain cause and an even less clear clinical presentation and disease process. This disease is clearly characterised not only by immense complexity, unpredictability and variability, but also by severe and pervasive suffering and discomfort.

Conclusion

Leading ME researcher, Dr. Jay Goldstein (1990: 17) describes ME as "a psychoneuroimmunologic disorder meaning it has elements of psychological, neurological and immunological dysfunction". The information presented in this chapter bears out Dr Goldstein's acute summary.

It is clear that this little understood illness affects the patient's mental processes and emotions, the brain itself, and the body's immune system. As a result, the ME sufferer is likely to experience the severe yet extremely variable physical and mental impact of ME as encompassing virtually every aspect of his or her functioning.

The impact of this experience on the person of the ME suffer will constitute the focus of Part IV.

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Chapter 3

Common misconceptions surrounding ME

The presence of so many medically unexplained symptoms have led some to conclude that ME is a psychiatric disorder rather than one with a clear physiological base. This is clearly reflected in the opinion of the noted American nutritionist and medical lawyer, Dr Victor Herbert, who has in recent times described ME as "an imaginary disease" (in Steincamp 1988: 5).

According to Macintyre (1998: 29) and Weinberg et al. (1994: 21) the origin of such a misconception of this disease can be traced back to the 1970s when two British psychiatrists, McEvedy and Beard, who took no account of the clinical features of ME, nevertheless described it as a serious psychological disorder. Despite obvious flaws in their reasoning, not to mention the fact that neither of them had interviewed or examined a single person afflicted with this disease, their psychiatric hypothesis was taken up by the media and has, unfortunately, been accepted without question by many members of the medical profession ever since.

In recent years, it has become apparent that this misconception generally results in ME being diagnosed either as hysteria or as depression.

The epithet of hysteria

The epithet of "mass hysteria", as first used by McEvedy and Beard, has been applied to several epidemic and sporadic cases of ME. Acheson (1992: 151) argues that in an illness in which there has been a selectivity for young women, no mortality, and few positive laboratory findings, it is important to examine the possibility that hysteria may indeed have accounted for part or all of the clinical picture presented by ME.

This author points out that a majority of cases may even constitute a hysterical reaction to a small number of cases of, for example, poliomyelitis. Thus, it will be readily admitted that an epidemic of poliomyelitis would produce overwork and emotional strain in the nursing staff of the hospital concerned. Many of the nurses would naturally feel apprehensive about

contracting the disease and may be inclined to misunderstand the minor aches and pains of everyday life. With the development of a few genuine cases of poliomyelitis among the staff and the resulting increased tension, it is possible to envisage an epidemic of hysterical paralysis (Acheson (1992: 151).

As Acheson (1992: 152) shows, an attractive case can indeed be made for such a hypothesis. The high attack rates in the most suggestible groups of the community, the predilection for hospital staff, and the association with preceding or concurrent outbreaks of poliomyelitis, might thus be explained. Clinically, the absence of or insignificant fever, the prominence of sensory phenomena which are admittedly often of bizarre distribution and content, the fluctuation of symptoms and signs from day to day, and the high incidence of negative cerebrospinal fluid findings would also fit in with this hypothesis.

On the other hand there are strong arguments against the idea that ME simply constitutes a mass hysterical reaction to a few cases of poliomyelitis. It does after all present a clinical picture characterised by physical signs that are quite unlike poliomyelitis. In addition, the relationship to poliomyelitis is not constant. Acheson (1992: 152), for instance, points to the Royal Free Hospital in 1955 where no patient with poliomyelitis had been admitted prior to an ME outbreak, nor was the diagnosis of ME entertained in the initial cases. There was thus no due apprehension about poliomyelitis among the hospital staff, but rather about infectious mononucleosis, which was the early diagnosis. Also, in the Coventry outbreak of the 1950's, six of the twelve patients had been nursing poliomyelitis cases for several years. It is therefore difficult to imagine why such experienced persons should suddenly manifest a hysterical reaction to poliomyelitis.

Acheson (1992: 152) further argues that the mental symptoms that appear to be a constant feature of all ME outbreaks and sporadic cases are not typical of hysteria. Disorders of consciousness and convulsions as may be seen in hysteria have been extremely rare. Shallowness of affect has also not been observed. On the contrary, depression and undue emotional lability have been the rule. In the acute stage terrifying dreams, states of panic, uncontrollable weeping and hypersomnia occur. During the convalescent stage the prominent features are impairment of memory, difficulty in concentrating, and depression. These symptoms are certainly more consistent with cerebral damage than with hysteria.

As a final point against the case for mass hysteria Acheson (1992: 153) points to the consistency of the course of the illness and to the similarities in the symptoms described, despite a wide variation in the type of community affected.

It is therefore clear that the clinical picture presented by ME in more than one respect strongly opposes any meaningful, let alone identical, comparison with the typical manifestation of hysteria.

ME as depression

Dutton (1992: 493) suggests that it is perhaps not only the complex clinical presentation of ME, but also the evasive nature of evidence in support of a viral cause for this disease, that has increased the tendency among medical practitioners to emphasise the role of depression in ME. According to Goldstein (1992: 401) these practitioners put ME "into the 'black box' of depression as a way of explaining the inexplicable".

As Dutton (1992: 504) remarks it is easy to see how the notion that ME is somehow caused by depression is seductive to medical practitioners. Such practitioners are after all mindful of the fact that somatization is one of the commonest and most troublesome problems encountered within the primary care practice. Hence, it becomes understandable why a disease that shows considerable symptom overlap with depression but has no clear physiological base, has often been misconceived as nothing more than a manifestation of depression.

The supposed connection between ME and depression is commonly investigated through studies which look for inflated prevalence rates of premorbid psychiatric problems in ME patients. According to Dutton (1992: 493) the presumed aetiologic implications of this search are that patients with premorbid depression have immunosuppression as a result of that depression, or have a constitutional neurologic weakness from which both the depression and ME arise, or have a tendency to somatize psychological problems with ME as yet another manifestation of that somatization.

However, according to Dutton's (1992: 468) review of recent literature, the case for depression consistently producing immunosuppression is weak, even when the immunosuppression is measured during the depression. Therefore, while some studies imply that depression

occurring at any time prior to the onset of ME may be serving some immunosuppressive function, research on depression and immune suppression does not support such a claim.

Furthermore, when depression occurs prior to ME onset, an alternative interpretation of immunosuppression is that both the depression and the ME are produced by constitutional neurological weaknesses. According to this argument, as conveyed by Dutton (1992: 499), ME reflects the interplay between organic and psychological factors in psychologically vulnerable individuals with a depressive diathesis. In other words, there is an inherited or constitutional tendency to react to illness with depression, and the depression prolongs the recovery period. However, Dutton (1992: 499) also indicates that evidence in support of this argument is weak.

The third premise of the search for inflated prevalence rates for premorbid depression is the assumption that ME represents a type of somatization. Dutton (1992: 500) however clearly shows that the characteristics of somatization disorder do not correspond with the clinical picture of ME. There is thus no strong evidence in support of an interpretation of ME as somatized depression.

In support of his argument, Dutton (1992: 493) point to a number of problems that arise in studies designed to examine the role of depression in ME. Dutton (1992: 493) firstly notes that chronic fatigue patients are not distinguished from ME patients although the theoretical overlap of depression with chronic fatigue (which has one symptom) is greater than the overlap of depression with the entire constellation of specific symptoms constituting ME. What is more, for patients with depression, their symptoms often appear to them to fall into a familiar (repetitive) pattern. This is not the case in ME. ME patients indeed experience their symptoms as wholly foreign, strange, bizarre, almost terrifying. In addition, the psychological problems that are sequelae of ME are very rarely clearly differentiated from premorbid problems. Also, the temporal relationship of depression to ME is not clearly specified. As such, psychological events that proximally preceded ME onset and more distant psychological events are inappropriately lumped together, even though they may have quite different theoretical significance in determining the aetiology of ME. To aggravate these problems, the findings that result from such studies are typically linked to evidence of immunologic suppression by depression, based on research that measured such suppression at the time of the depression, not years after the depression. Hence, the net effect is to convey the impression

that depression may play a greater causal (presumably immunosuppressive) role in ME than is warranted by the data.

In addition, the validity of research findings that imply such a causal link between ME and depression may be further jeopardised by the modes of scoring on psychiatric instruments. Jason et al. (1997: 974-975) explain this problem with reference to the Diagnostic Interview Schedule (DIS) which, although not designed for use with medically ill populations, has frequently been used to assess psychiatric comorbidity in ME samples.

Within this context, if a respondent mentions that a symptom on the DIS (e.g. pain in arms or legs) is due to a medical problem that was diagnosed by a physician, DIS rules indicate that this problem should not be counted as a psychiatric problem. If the physician attributed the patient's symptoms to nerves or a psychiatric disorder, the patient automatically receives a score counting towards a psychiatric diagnosis, regardless of whether the patient agrees with the physician. In addition, if several physicians diagnosed a patient as having a medical disorder but only one physician attributed the symptom to a psychiatric disorder, the item would be scored to count towards a psychiatric diagnosis (Jason et al. 1997: 974).

Since many physicians still do not accept ME as a legitimate medical disorder it is possible that many patients would have had at least one physician who diagnosed their medical complaints as being a psychiatric disorder, thus increasing the likelihood that people with ME would receive a psychiatric diagnoses. This clearly suggests, as Jason et al. (1997: 975) recognise, that high or low psychiatric rates in ME samples may be a function of whether symptoms are attributed to psychiatric or non-psychiatric causation.

In addition to such pertinent research problems, the supposed connection between ME and depression is also questioned by the symptom picture typical of ME. In this regard, Dutton (1992: 502) indicates that ME symptoms have indeed been reported that appear to differ from the symptoms of depression or somatization. One of these symptoms is muscle weakness specifically in response to exercise (as opposed to general lethargy associated with depression). Typically, the ME patient tolerates the physical exertion reasonably well and may even feel energised during and immediately after the exertion. However, 6-24 hours later the patients feel ill, the involved muscle group feels sore and weak, and patients experience marked worsening of their fatigue, cognitive function, and fever. It appears as though this pattern of post-exertional malaise, followed by a striking exacerbation of symptoms, is unusual

in healthy individuals and in those with diseases that have some clinical similarity to ME, including depression.

According to Dutton (1992: 502), a further distinct symptom of ME concerns information processing deficits. ME patients, for instance, report being unable to function socially because of a sense of information overload in social groups, leading many to the reclusive existence that frequently accompanies this disease. In addition, unlike depressed patients, ME patients can handle dyadic interaction but not group interaction that requires constant switching of attention. ME thus arises as a discrete illness with symptoms not typically found in depression or somatization.

However, this assertion does not deny the existence of ME comorbidity with depression.

In this regard, Dutton (1992: 502) points to the work of Derogatis and Wise (1989) in which these authors argue that depression accompanying a prolonged debilitating illness might be more appropriately conceptualised as demoralisation or despondency, rather than as a discrete psychiatric disorder. This may be particularly true, as Jason et al. (1997: 980) note, in the case of an ambiguous illness such as ME in which patients have difficulty gaining recognition that they are suffering from a legitimate non-psychiatric illness. This view is strongly supported by Macintyre (1998: 173-174).

More support for this view is also offered by Dutton (1992: 501) and Steincamp (1988: 128) who argue that ME patients' grave apprehension about their illness is not unfounded. After all, ME can be a highly incapacitating disease that renders their occupational, educational, social and personal life difficult, if not impossible. It has an uncertain duration and prognosis, it recurs cyclically and unpredictably, and is often met with scepticism by physicians and others. Such effects would seem sufficient to explain the episodes of depression that ME patients might experience.

Conclusion

Despite ongoing (and, it appears, at times unsubstantiated) debates, the discussion above makes it possible to conclude that ME is neither a manifestation of hysteria nor a result of depression. Instead, it is much more likely that ME will follow a path similar to that of a

variety of other medical disorders, including multiple sclerosis, which was initially conceived in terms of a psychological model, but was eventually found to stem from a clear organic cause (Dutton 1992: 503). For this reason, we should heed Dutton's (1992: 504) caution against assigning a causal role to psychological variables in the aetiology of ME. If we do not, a better understanding of this illness – and of the suffering that accompanies it – may very well remain elusive.

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Chapter 4

The social impact of ME

Besides investigating the nature of the disease itself, it is equally important to understand the individual's personal experience of ME.

It is therefore important to reflect upon the ME sufferer's encounters in the social sphere - with the medical profession, with family and friends, and with society at large – as these are explicitly shaped by the illness. The discussion will then turn its focus on how these encounters provoke and amplify the Self's experience of this illness.

Encounters with the medical profession

The ME sufferer's personal experience of this illness is closely related to the medical profession's response to it.

Fennell (1995: 163-164) notes that medical problems or illnesses that do not have a distinct beginning, middle and end, and are not easily treatable, upset a growing view in the health care system that real problems are uni-causal and will respond to a magic bullet approach. Illnesses such as ME with its unclear aetiology, course and outcome are thus frustrating, potentially expensive and consequently disparaged.

The frustration experienced in dealing with ME largely stems from the duality in the approach to patient care by medical practitioners. The Cartesian split has created an elevation of that which is physiologic, observable and organic, above that which is psychological, non-observable and inorganic. Organic processes are viewed as "real" or legitimate, while inorganic processes are seen as "unreal" and illegitimate. Consequently, in assessment situations, patients' problems that do no meet the criteria of organicity (i.e. genuine) are relegated to psychological, inorganic sources (i.e. not genuine or unreal). This view has been expressed many times in the clinical expression, "I could not find anything wrong with him; it must be in his head". This division of psyche and soma unintentionally becomes particularly problematic for ME patients who suffer physically, cognitively, and psychologically (Fennell 1995: 165-166).

As Fennell (1995: 166-167) observes, ME as a disease involving both psyche and soma, can prove to be an often unmanageable problem for the medical practitioner working within a split mechanistic approach. Without a specific aetiology, a technologically-based diagnostic marker, or a proven treatment protocol, treating ME patients can thus be a truly frustrating experience for the medical practitioner – one that does not allow him or her to perform "competently". This frustration is easily communicated to the patient; indeed, it often leaves the patient feeling inadequate, dejected and helpless (Vorster 1996: 49).

The incompetence of the medical profession in dealing with ME is particularly reflected in the lack of adequate treatment models. Fennell (1995: 164) illustrates this by pointing out that many psychological methods for coping with grief and loss, implicitly or explicitly, infer an end point in the loss experience beyond which an individual can experience resolution or acceptance. However, for ME patients the experience of this illness teaches them that even though they may valiantly struggle through the stages of loss, they may have their hard-won acceptance shattered at the onset of yet another relapse cycle.

Aside from the dire state of incompetence and frustration encountered within the medical practitioner's office, ME sufferers may also be confronted with a perception that they are not suffering from a real, organically based disease. As Fennell (1995: 166-167) and Weinberg et al. (1994: 21) show, the medical community is after all still very sceptical of this disease and may, by not reaching a medical diagnosis in some instances, refuse to bestow recognition and legitimacy on those who suffer from ME.

These difficulties with the recognition, assessment and treatment of ME may eventually convey the impression that the medical practitioner suspects that the patient is suffering from a flawed character. What may begin as a suspicion of a psychological or somatization disorder may thus become an allegation of deliberate malingering (Fennell 1995: 167).

In response patients are, according to Fennell (1995: 167), likely to experience confusion regarding their identity and about what is "real": "Am I sick?" "Am I well?" "Am I crazy?" Indeed, their struggle with the moral implications raised by a medical consultation, augmented by the intensity of the diagnostic controversy and the lack of appropriate approaches to treatment, begins to erode the patients' ability to determine what is helpful and what is not, who is trustworthy and who is not.

After all, in their encounters with medical practitioners, patients seek healing and relief from the burden of illness. Yet such healing cannot occur where the practitioner fails to recognise that the patient is ill (Murdoch 1992: 97). Hence, instead of finding healing or, at the very least, solace, patients are far more likely to come away feeling confused, blamed, frightened, or even vaguely immoral or "bad".

In addition, when faced with a medical world that insists that ME sufferers are not sick or that they suffer from some psychological disorder, patients may be prone to experience overwhelming feelings of guilt. Sufferers sense that they themselves are somehow responsible for becoming and being so ill (Rubenstein 1992: 101-103). As Fennell (1995: 164-165) points out, this experience of guilt is compounded by the financial sacrifices demanded for the care and management of their seemingly non-existent illness.

Such "ambiguity of medical status" (Weinberg 1994: 21) can clearly be expected to engender a devastating level of psychological stress that simply serves to complicate the ME sufferer's condition even further. Hence, because of these potentially traumatising experiences, many patients decide to avoid medical practitioners entirely.

Within the circle of family and friends

Because of the lack of knowledge and understanding of ME prevalent within the medical world, the ME sufferer is likely to turn to his or her circle of family and friends for support.

However, even here ME may prove to represent a significant source of stress. Macintyre (1998: 350-356) explains that the illness of any member of a family inevitably adds to the strain on relationships. If a family member has an acute illness, an injury or has had an operation there is an expectation that he or she will get better after a predicted period of convalescence and will return to a more or less normal life. However, suffering from ME is a sentence of unknown duration. The unknown, combined with the variability and unpredictability of this disease, is thus likely to have a disruptive influence on relationships within the family and particularly within the marital unit. According to Vorster (1996: 46), this disruption is also apparent within the friendly relationships that constitute the ME sufferer's broader base of social support.

Fennell (1995: 164-165) reports that family and friends often put pressure on ME sufferers not to talk about their illness or any ME-related topics. Family and friends may indeed change the subject, avoid asking the patient how he or she feels, or censor how patients describe their illness experience. For example, a family member may only allow the patient to describe how he or she has improved physically over time or how the illness has changed his or her life for the better.

The patient's communication with family and friends is thus likely to change as it becomes less open and less frequent. Vorster (1996: 45-46) illustrates that the patient may, for instance, develop a reluctance to express strong feelings such as anger or depression for fear of alienation, leading to even more unexpressed frustration and despair.

These feelings are intensified by the pressure put on sufferers to avoid appropriate measures of self-care, such as limiting physical exertion and conserving energy in order to heal. Instead, sufferers are likely to be urged by family and friends to "get back to normal" and to engage in activities that will only exacerbate their condition (Fennell 1995: 164-165).

Fennell (1995: 164-165) argues that such pressure for non-disclosure and the encouragement of inappropriate measures of self-care, though often veiled as concern for the patient, usually stem from fear and anxiety produced in family members and friends who observe the ill person. This is confirmed by Vorster (1996: 45 & 54) who points out that family members and friends are, in addition to fear and anxiety, very likely to experience feelings of inadequacy and uncertainty in performing treatment, preventing complications or meeting daily needs. Unfortunately these feelings are easily transferred to the patient.

In response patients often begin to avoid intimacy and start attempting to "pass" for a healthy person. The ill person feels forced to construct a "normal" public persona, while the more genuine persona is only shared with a few individuals, if any. Fennell (1995: 165) explains that sufferers may "stay in the closet", much in the same manner as many gays and lesbians did, in an effort to protect themselves from stigmatisation. The pressure of living a dual existence with its concomitant rejection of Self, loss of esteem and depression frequently leads to further avoidance of intimacy and increased isolation.

However, as Vorster (1996: 40 & 58) repeatedly points out, the effect of support by family and friends on the ill person's ability to cope with this disease can indeed be impressive. Such

social support can, after all, provide a buffer that protects the patient from the effects of other sources of stress. Social support can thus be invaluable to the ME sufferer.

Facing society's response

Although the sufferer's personal experience of ME may clearly be traumatic, aggravated as it is by the response to it by the medical world, family and friends, society's response to the illness may precipitate a secondary trauma with even more far-reaching and long-term consequences (Fennell 1995: 160-161).

Fennell (1995: 161) places this social response into context by explaining that the socio-cultural factors that influence ME patients converge within the cultural framework of society and create a social context and discourse which dictate social beliefs and attitudes toward illness and the treatment thereof.

Engulfed within this framework, persons with ME are likely to encounter beliefs and attitudes that are stigmatising and sometimes traumatising.

According to Fennell (1995: 161-162) these beliefs and attitudes toward ME arose within an inhospitable environment ravaged by the fear of AIDS. Society was therefore primed to dismiss yet another disease with an unknown aetiology and was quick to negatively label the supposedly affluent minority who contracted it. This response clearly reflects society's intolerance of what is not understood.

Fennell (1995: 162) explains, "A contributing factor to this cultural intolerance has been the elevation of ... quantitative systems of knowing, combined with the devaluation of qualitative or experimentally guided systems of knowing. In this conceptualisation, all that is true or real is observable, measurable and ultimately knowable. Anything that does not yield to these criteria is suspect. This cultural elevation of the quantitative and allegedly objective, above the qualitative and subjective, has contributed to the view that ambiguous situations or problems are somehow dangerous and possibly immoral, and therefore should be avoided".

Fennell (1995: 162-163) highlights the "just world" notion as a common manifestation of this intolerance to the yet unknown. In accordance with this notion members of society

automatically distance themselves from someone they meet or read about in the media who has suffered much. By specifying how they would have avoided the situation, solved it or responded to it differently, they create a comforting belief that personal tragedy can be avoided by utilising far-sighted protective action. This rationalisation creates a false sense of calm and control over the uncertainty of living, and makes it easier to blame the victim.

This closely relates to suspicion, which represents one of the most immediate negative attitudes encountered by ME sufferers. This ill-defined, negative emotional tone of wariness and prejudgement is often reinforced by researchers such as Abbey and Garfinkel (1991: 1644) who claim that the diagnosis of ME merely provides a legitimate "medical" reason for sufferers' collection of psychophysiological symptoms, and allows them to withdraw from situations they find intolerable on the basis of illness, rather than by their own volition. "Illness and the sick role are thus the only socially legitimate excuse for abandoning the workplace and the pursuit of achievement" (Abbey & Garfinkel 1991: 1644).

In addition, it is also often claimed that those who suffer from ME have some unconscious need to be passive and dependent which is fulfilled and sanctioned by illness. For instance, ME may "legitimise" changes in family systems that enable patients to avoid stressful situations like work and to fulfil their need for dependency by becoming passive recipients of care by others (Dutton 1992: 500-501).

However, Apfelbaum (1992: 1754) and Saltzstein et al. (1992: 1755) strongly contest such assertions which imply that ME is somehow both attractive to and has social value for those who suffer from it. "This is simply absurd. We have rarely seen secondary gain or social value associated with chronic fatigue syndrome. The price of chronic fatigue syndrome, as with other chronic illnesses, is loss and estrangement from 'normal' life" (Saltzstein 1992: 1755). These authors argue that ME is, instead, far more likely to engender an experience of shame, frustration and stress because of the inability to function at pre-illness levels.

This is confirmed by Macintyre (1998: 29-36) who asserts that, contrary to popular belief, those who struggle with this disease are generally highly motivated individuals who are immensely frustrated by not being physically and mentally able to do things as before. The loss of an ability to function in nearly every aspect of life cannot by any stretch of the imagination cause people to lead happier lives than they could do otherwise. The actual illness

experience associated with ME may, as Dutton (1992: 501) concludes, indeed greatly outweigh any vague possibility of secondary gain.

The damage done to those who suffer from ME through such false presentations of the disease within society has been incalculable (Macintyre 1988: 29). According to Fennell (1995: 162-163), sufferers are likely to experience a sense of shame as their esteem begins to erode under the pressure of the suspicions about ME that prevail in society. Sufferers may also, as is the case with exposure to the medical profession, experience a sense of guilt as they internalise society's message that they have caused this problem by some personal action and therefore deserve to be ill. Under such circumstances the sufferer's sense of control is clearly likely to dwindle, leaving them to feel increasingly powerless.

Unfortunately, this experience is intensified by the media which functions as a vehicle that powerfully reinforces societal prejudices and stereotypes (cf. Burns 1999; Editor 1998: A14; Wessely et al. 1998: 310-312). Such negative media coverage of their suffering is likely to amplify ME sufferers' emotional distress, with attendant feelings of shame, grief and a loss of worth (cf. McLaughlin 1999: A11). It therefore becomes clear why so many ME sufferers take refuge from society's response to their illness by increased social isolation (Fennell 1995: 168).

The Self and ME

Very often, as Macintyre (1998: 8) explains, the ME patient "cannot believe that this pathetic creature whose muscles don't work, whose brain is like porridge, who cries from pain and exhaustion from doing nearly nothing can be the same fit and active individual he or she was before". ME sufferers, as well as their family and friends, clearly experience great difficulty in reconciling this new awareness of Self with what was expected of the former "normal, healthy Self".

Vorster (1996: 45 & 55) correctly observes that when the self-image and self-esteem of the ME sufferer change during the course of this illness, this in itself can develop into a source of stress. Macintyre (1998: 130-131) speculates that such change may not only be related to the illness itself, but indeed also to the achievement-oriented culture of modern society in which

"having boundless energy" has almost become morally desirable – something which is however beyond the reach of many ME sufferers.

Furthermore, changes in the self-image of the ME sufferer may also be strongly influenced by the media's designation of ME as "yuppie flu". By characterising sufferers as "yuppiefied" upper middle class women who were greedily trying to "have it all" and, as a result, just got what they deserved, the media in effect relegate this disease to a level of travesty in the popular mind (Weinberg et al. 1994: 21). Sadly, such repeated media characterisation has paved the way for a stigmatisation and stereotyping of the ME population which has found its way into the public mind (Fennell 1995: 167).

Weinberg et al.'s (1994: 23) report suggests that ME sufferers unfortunately tend to identify very closely with these negative public stereotypes. This identification may be related to the possibility that ME sufferers constitute a unique social grouping which they are unable to leave because of their illness. Until they recover they are thus forced to remain within their "group" and to live with the negative connotations involved in their public stereotype.

Weinberg et al. (1994: 23) found that ME sufferers generally attach such weight to their public stereotype that medical diagnosis alone does not seem to improve their respondents' self-image. It thus appears as if the medical controversy surrounding ME has, as Weinberg et al. (1994: 25) explain, eroded the potentially positive impact a diagnosis may have on self-image. The reason is that other doctors as well as lay-people may regard a ME diagnosis as a "quirk" of a particular doctor, or a term attributed to a host of symptoms to which a doctor cannot assign a definite diagnosis, or even a label attached to satisfy a hypochondriacal patient. It is, therefore, rather the public perception of ME and of ME sufferers which is considered to be more important. This leads Weinberg et al. (1994: 23) to conclude that it is the "public acceptance of ME which has the legitimising effect, not the diagnosis; medical diagnosis merely acts to facilitate the process of public acceptance".

Conclusion

It is evident that the personal experience of ME does not leave any aspect of the sufferer's life untouched. The sufferer's experience of an "ill Self" is directly exposed to (and augmented

by) the complex and interwoven influence exerted by the medical world, by the sufferer's family and friends, as well as by society and the media.

It appears that the nature of the sufferer's experience of the social world and of the Self is largely determined by the prevailing lack of knowledge surrounding ME. This deficiency leaves a vacuum too easily filled by suspicion and prejudice.

This situation can clearly be to the detriment of all sufferers – and should hence be rectified.

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Summary

The most pertinent concern throughout the discussion presented in Part I is the appalling lack of knowledge surrounding virtually every aspect of ME. This lack of knowledge has stimulated tremendous controversy and confusion, specifically with regard to the aetiology and pathophysiology of ME.

This lack of knowledge, the inability to deal with the unknown, and the almost unlimited variability and unpredictability of ME, have also led to insinuations that this disease is purely imaginary or that it can simply be ascribed to a psychiatric origin. ME is thus still often denied the right to claim a legitimate place within the medical and social worlds.

These misconceptions, which give rise to unfounded suspicion and prejudice, have apparently permeated every dimension of society and have certainly been strongly reinforced by the media.

Unfortunately these misconceptions have also been transferred to ME sufferers who may, as a result, feel virtually deserted in their struggle to deal with the incapacitating severity of this disease. Indeed, instead of much needed support and understanding, they are more likely to be left to feel confused, blamed, powerless and even immoral.

Hyde (1992d: 694) states that, "until now, patients with M.E./CFS... have been largely forgotten". This situation clearly needs to be addressed through sensitive research directed at developing greater insight into the deeply personal experience of those who suffer from this debilitating disease. As discussed in Chapter 4, such research should encompass a focus not only on sufferers' own experience of the illness, but also on their encounters with the medical profession, with family and friends, and with the media and society, because such encounters directly shape the nature of that experience. Such a comprehensive study will provide a firm basis for increased support for and greater understanding of ME sufferers worldwide.

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PART II

Introduction

In their pursuit of doing justice to the particular social reality being studied, social researchers offer an understanding – a theory – based on the situations, actions and meanings of the actors, the participants, themselves. It is a theory directed at offering a new way of looking at or even of improving participants' reality. In following this tradition, I will present in Part IV a description, a theory, of the experiences related by those ME sufferers who had chosen to disclose their social reality to me. But wherein lies the value of this theory, of my *theory?*

Is the value of a theory based in the respect it pays to the procedures of scientific practice? As Blum (1979: 303-304) traces the origin of "theory", it appears that this is but a small part of the answer. Indeed, "theory" or "theoria" by far supersedes our various practical conceptions of science and scientific procedures. "Theoria", as Aristotle used the term, described a "kind of mental activity in which we engage for its own sake, as contemplative: to theorize meant to inspect or to keep one's gaze fixed on. To theorize was to turn one's mind in a certain direction, or to look at the world under the auspices of a certain interest... Even before this usage, however, theoria referred to the envoy sent to consult an oracle and was the title of the collection of state ambassadors that a city-state delegated to attend the sacral festivals of another city-state. According to some sources, since these festivals were usually connected with games, theory came to mean spectator and, more particularly, a traveller who visits foreign places to learn something about their customs and laws. Because the witnessed events were usually connected with divine things, theory came to be seen as a particularly sublime way of life... Theoretical life meant more than science because it was not conceived as arising from mere curiosity or from practical necessity, but out of wonder, as an attempt to escape from ignorance". As a process originating in wonderment and encapsulating the ideas of spectator, search and Self, theorising was (and still is) a far more inclusive and powerful notion than scientific practice itself. The value of a theory (and of my theory) therefore, does not only *lie in the homage it pays to scientific procedures as we currently understand it, but in the attempt to broaden understanding, to offer an alternative way of knowing a social reality.*

If we accept that to theorise is to present a particular way of appreciating a social reality, how then do we ensure that a theory, far from "escaping ignorance", is not simply inventing

another realm of the same kind? Stated differently, how can I be sure that my theory, as my *story of* their *experiences, carries any truth-value?*

Until recently, and for many years before that, social researchers have answered this question by relying on the concept of "objectivity". Objectivity was used with reference to their research procedures and findings to imply, as Bittner (1973: 109-110) shows, that "what they did was altogether true, important, interesting, rigorous, lucid, useful, and whatever else could conceivably matter in their favor... In the then prevailing opinion, strict compliance with certain canons of objectivity alone guaranteed the attainment of all the objectives of rational inquiry". The value of my theory – and of any research-based theory for that matter – would therefore depend upon how "objective" it was judged (or could be presented) to be.

But, as I will show in the chapters to follow, this view of theory as solely of value when pronounced "objective", omitted a central component already identified by the Greek theoretical masters: the Self *of the theoriser in the theory. As a result of this oversight, "objectivity" has in some quarters of the sociological discipline "fallen into ill repute and is explicitly denounced; in many parts of the discipline the problem of objectivity is treated as insignificant and uninteresting; and even where the criteria of objectivity are adhered to in the inherited sense much less is made of it than used to be the case" (Bittner 1973: 109-110). Yet, neither contempt for nor neglect of objectivity adequately addresses the still lingering question concerning the actual truth-value of a theory – of my theory. Moreover, a reaction that renounces the failures of "objectivity" does not exempt researchers from the responsibility of openly recognising (and dealing with) the contribution of the Self in the process of theory development.*

The very fact that I *– the researcher and theoriser –* and *the fellow ME sufferer – is directly involved in the entire research process – in each encounter with participants, in the interpretation of each word, in the construction of each paragraph – means that my contribution to the theory I develop in Part IV cannot be ignored or omitted. The in-depth study of the personal and social experiences of those who suffer from ME could not, after all, have been conducted without consideration of my personal stake in such a study. I never was, nor pretended to be, a researcher conducting a study from a completely detached and uninvolved point of view (if such a view would indeed be possible). Instead, I was a researcher conducting a study from the perspective of suffering from ME myself.*

This fact – that I am a ME sufferer and have been so for the past eight years –immediately questioned the degree to which I would be able to conduct an "objective" study that could possibly result in valid findings concerning the personal and social experiences of other *ME sufferers. Would my own subjectivity as a ME sufferer not cloud my judgement and impair my ability to achieve an unbiased account of other ME sufferers' experiences? Du Bois (1983: 105) does after all remark that "the closer our subject matter to our own life and experience, the more we can probably expect our own beliefs about the world to enter into and shape our work – to influence the very questions we pose, our conception of how to approach those questions, and the interpretations we generate from our findings".*

With this possibility in mind, a number of pertinent questions now demanded to be answered: Does my description, my interpretation (or is it transformation?) of my participants' reality, reflect their actual experience of ME? Is it an understanding of their words as such, independent of the circumstances of their conception? Is it purely a mirror of their reality as related to me? Or is it an understanding reconstructed within the framework of a particular conceptual theory? Is it a construction more of my own doing than of theirs? In short, is it a story that holds any truth?

For me, to answer these questions and so to determine the truth-value of my story is difficult. I was, after all, just as present and involved in the interview and interpretation process as I am now in composing the present description. Yet, far from offering any escape, this difficulty simply serves to re-emphasise the need for me to find adequate answers to the questions posed above. And as a first step in taking up this challenge, I present a discussion in Part II directed at developing a clearer notion of the concept of "truth" or "truth-value". Once we have a better idea about what we mean when we use this concept, we will be able to more competently evaluate the "truth-value" of my story – as well as the influence on it of the "I" who researched it – in Part V.

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Chapter 5
What counts as truth?

Potter (1996: 53) refers to the work of Melvin Pollner (1987) and in particular to Pollner's notion of "mundane reason". The principle idea behind this concept is that "when we are discussing features of our world with others – what went on, who did what and so on – we make a fundamental assumption. We assume that we all have at least potential access to the same underlying reality. Any neutral, competent observer, placed in the same position, will see the same thing". At first sight we may consider it odd to talk of this as a form of *reason* for, surely, we might think that this is just the way things are; it is just the simple truth. However, "Pollner puts quite a lot of work into convincing us that this is indeed a form of reasoning, a specific method for understanding; and, moreover, that it is one which is fundamental because it is at the centre of a web of beliefs about reality, Self and other people" (Potter 1996: 53-54).

Mundane reason lies at the very foundation of our everyday lives – and at the heart of virtually all social research coveting "the truth". Very importantly, it reflects our quest for reality, for a true, reliable, authentic world. It is "the quest for a final assurance of absolute truth on which we can base our lives and our society" (Clarke 1996: 19). But what exactly is this concept of "truth" that is constantly on our lips and on which we stake so much? Through the exploration of this concept presented below, I hope to offer insight into a possible answer to this question.

A reflecting mirror... or a constructive construction?

Potter (1996: 97) speaks of "the clash between two metaphors". By this he refers to two opposing conceptions of what we might count as truth and reality. In this clash the "mirror metaphor" comes up head to head against the "metaphor of construction".

The mirror metaphor

The mirror metaphor states that "there are a set of things in the world which are reflected onto a smooth surface, but in this case the surface is not glass but language. Language reflects how things are in its descriptions, representations and accounts. And as these are circulated in the

world of human affairs they may be treated as accounts which are reliable, factual or literal, or, alternatively, the mirror may blur or distort as in the case of confusion or lies" (Potter 1996: 97). In other words there is only one true and complete description of "the way the world really is". It is this description – the absolute truth – which language more or less successfully reflects. Consequently, scientific theorising is intent on providing a statement which most truthfully "copies" or "corresponds with" the ultimate description of reality.

The mirror metaphor appears to be backed up by an extensive history of thought in both society and science. Here, one of the most dominating influences has been "objectivity" – a notion closely associated with the positivist view of social reality as "objectively constituted" (Stanley & Wise 1983: 193). According to this view, there is only one true "real" reality which can come into focus and be reflected accurately – that is, objectively – only if the researcher removes him- or herself from any involvement in what is being investigated. In fact the researcher needs to "epitomize neutrality and impartiality" by becoming "the emotional, cognitive, and moral equivalent of a blank slate" (Rosaldo 1993: 168). This points to the central assumption underlying objectivity: that "research can only be valued and reliable if all subjective 'variables' – all presuppositions, preconceived notions and valued – are suspended or bracketed" (Mouton 1999: 286).

Mouton (1987: 2-3) traces this notion to the view shared by Bacon and Descartes that the researcher should deliberately rid him- or herself from all human subjectivity, specifically in the form of prejudices and preconceived notions. He shows that this view was ultimately developed and elaborated into a major "offensive" against all forms of subjectivity, which include not only prejudices and preconceived notions, but also the researcher's values, interests and emotions. According to Mouton this "offensive" was soon to be followed by the definition of objectivity as the "emancipation" of all subjective variables.

The presumably hazardous nature of subjective variables can be related to Bacon's argument concerning the "Idol of the Cave" as one particular source of false opinion. According to Merton (1972: 30-31), Bacon suggests that the immediate social world in which researchers live seriously limits what they are prepared to perceive and how they perceive it. Dominated by the customs of their group, they maintain preconceived opinions, distort their perceptions to make them agree with these opinions, are hence held in ignorance and are so led into errors which they parochially mistake for "the truth". Therefore, access to "authentic truth" is only made possible once researchers "escape from the cave" and so extend their vision. By

implication it is only through the "iconoclasm that comes with changing group affiliations that we can destroy the Idol of the Cave, abandon delusory doctrines of our own group, and enlarge our prospects for reaching the truth" (Merton 1972: 31).

Apparently in close association with and "oddly reminiscent" (Merton 1972: 23) of the Baconian doctrine, Simmel developed and promoted the thesis of the researcher as "the stranger who moves on". The "stranger", who is not caught up in commitments to the group and who is therefore "freer, practically and theoretically" (Simmel in Merton 1972: 32), can more readily acquire the strategic role of the relatively objective investigator. Indeed, it is argued that the researcher as stranger "surveys conditions with less prejudice... he is not tied down in his action by habit, piety, and precedent" (Simmel in Merton 1972: 33). Such a researcher would then epitomise the "ideal of objectivity" (Acker et al. 1983: 427) by removing the point of view of the observer from the research process so that the results – that is, the image reflected in the mirror of language – will not be biased in any way by the researcher's own subjectivity.

Science in the modern world has majestically (and with astounding credibility) lived up to this task. In the process it has created an impersonal world that is "really" largely indifferent to us, "going its own mechanical way, its blind and random consequences only labelled as weal and woe in our own eyes. We can neither propitiate nor befriend the real world. It goes its way entirely unaffected by our pleas and cries" (Clarke 1996: 22). Still, Clarke (1996: 22-23) points out, "we need to go back only a few hundred years, or move only a little to a different culture, to see how distinctive this view is. In the majority of cultures, for the majority of history, humanity has thought quite differently, holding that the world was essentially animate, as open to influence by me as is another person. It was either pervaded by spirits, or it was under the control of the divine providence of God in all its details. The change from the old animistic or theistic view to the modern view was very much the result of the rise of science in the late sixteenth and seventeenth centuries... Science proposed a picture of the universe as a vast machine, built up from tiny atoms in the way a clock is built up from cogs". Driven by this view, science systematically set out to develop a picture – a mirror image – of reality. It was an image from which "frivolous" human elements, such as human emotion, human sway, and human motive – in short, all "humanness" – were firmly excluded. The single reality reflected in the mirror of science was objectively situated "out there", independent of all human import.

In this respect the mirror metaphor again aligns with the notion of objectivity by specifically insisting on a 'separation between the knower from what he knows' (Stanley & Wise 1993: 163). This suggests that the mirror metaphor has come to rely on a "subject"/"object" dichotomy. According to this dichotomy, what is studied is described as the "object" – the "other" who is "out there". The "object" is "irrational, incapable of scientific thought or use of scientific techniques, and instead have 'commonsense understanding' (read 'misunderstanding')" (Stanley & Wise 1993: 114). In contrast, the "subject" is the researcher who stands back from the object and does research "on" the object in an objective and dispassionate fashion. The "subject" represents the true scientist, the one who sets goals, devises rational means of achieving these, and investigates social reality by using scientific techniques and modes of thought in order to uncover "the" truth (Stanley & Wise 1993: 114).

The distance implied by this dichotomy between the researcher and what is researched needs to be maintained at all times "since any involvement or interaction between 'subject' and 'object' could lead to biased and prejudiced research" (Mouton 1999: 286). Therefore, a position of non-involvement or at least of very little involvement is understood to enable the researcher to remain in control of the quality of the research data. As a result, the detached researcher is expected to be able to offer an objective and scientifically verifiable account – a perfect mirror image – of the social world being studied; an account devoid of the bias that may stem from subjective involvement within the research context (Oakley 1981: 31-41).

Central to the mirror metaphor of modern science is the view that there is only one reality to be reflected in the mirror. Science represents one progressive extension of knowledge into the darkness of the "not-yet-reflected". In other words, science is regarded as working away at "the coal-face of knowledge, making hypothesis and testing them in order to cut into each new seam of phenomena that emerged. Sometimes progress was gradual, sometimes it came in a sudden spurt, but all the time it was a cumulative effort, each worker systematically extending the work done in the past. Once part of the darkness had been claimed for knowledge, then that area of truth stood valid for all time" (Clarke 1996: 27). In other words, for reality to be truthfully revealed, it merely has to come under the gaze of a competent scientist obligingly looking into the mirror. As the theories developed by such a scientist "mirrors" the objective ordering of reality independently of all humanness they are, in a word, "true", or assumed to be true.

Thus, as Clarke (1991: 21) observes, our society (that is, modern society) has for a very, very long time been founded on "the view that there is a single solid reality, that truth is a matter of agreement with reality, and that science is a procedure for determining the nature of reality and for judging the truth of factual statement". In other words, when *the* truth is reflected in a mirror, science is appointed as both the sculptor of the ideal mirror image as well as the judge presiding over the truthful clarity of each image reflected.

After only a brief review of the mirror metaphor a number of potential areas of dispute and controversy immediately springs to mind. But I postpone a consideration of these until I have established the qualifications of the opponent challenging the mirror metaphor. I now turn to the "metaphor of construction".

The metaphor of construction

The metaphor of construction described by Potter (1996: 97-98) operates on two levels when applied to descriptions of the world, or of reality. Such descriptions may be treated either as *constructive* or as *constructions themselves*.

On the first level, the idea is that descriptions and accounts *construct the world*, or at least versions of the world. The strongest version of the construction metaphor in this form would have the world literally springing into existence as it is talked or written about. Ridiculous, surely! How can we simply "invent" the world through the spoken or written word? Ridiculous perhaps but, like Potter, I want to opt for something similar though not quite as strong. Reality (and what counts as "truth") "enters into human practices by way of the categories and descriptions that are part of those practices. The world is not ready categorized by God or nature in a way that we are all forced to accept. It is *constituted* in one way or another as people talk it, write it and argue it" (Potter 1996: 98). That is, through describing our world as we do, we are giving life to a particular version of it.

In terms of the construction metaphor, the material world (which it acknowledges as "real") is constantly shaped and interpreted through human actions and consciousness. As such, this approach insists that there is room for a variety of interpretations and meanings, that behind what is taken as "knowledge" lies social processes, and that such processes involve constant negotiation and renegotiation (cf. Jordanova 1995: 368). Hacking (1999: 2) maintains that this notion of the social construction of knowledge can be "wonderfully liberating". It reminds us

that concepts such as, say, "motherhood" and its meanings are "not fixed and inevitable". This recognition allows mothers to discover that "the ways they are supposed to feel and act are not ordained by human nature or the biology of reproduction" (Hacking 1999: 2). This renders them liberated from the obligation to obey the rules of "motherhood" and "family" prevalent at the time. Thus, by regarding descriptions and accounts as but human constructions, we become able to recognise the possibility of different versions of the same world. That is, the metaphor of construction helps us to recognise that there might be, and most likely are, different ways of seeing and understanding the social reality under our gaze.

In raising our consciousness about the status of specific claims to the truth, the approach offered by social construction typically becomes inherently critical of the status quo. Hacking (1999: 6) explains that social constructionists tend to hold that X (or more accurately, the *idea of* X) need not have existed, or need not be at all as it is. That is, "X, or X as it is at present, is not determined by the nature of things; it is not inevitable". Very often they would go further, and urge that "X is quite bad as it is", and even that we would be much better off if X were eliminated or at least "radically transformed". Here, the argument clearly departs from the assumption that X was brought into being or shaped by social events, forces, and history, all of which could have been different. While X, although recognised as inevitable need not be bad, Hacking (1999: 7) holds that those who use the social construction idea enthusiastically and typically *do* want to criticize or change X. Thus, a recognition of the world – and of claims to the truth specifically – as not simply given but rather as constructed by us, helps us to recognise that there are different – and even better – ways of seeing. Yet, this recognition is only of value if, "in the present state of affairs, X is taken for granted", that is, if "X appears to be inevitable" (Hacking 1999: 12). If everyone already recognises that X is a result of social events, there would hardly be any point in even talking about social construction. In other words, to be employed meaningfully, the construction metaphor requires, as a "precondition", that X *appears to be inevitable*. Where this is the case, the construction metaphor will enable us to change the ways we see and to advance understandings that do not necessarily correspond with the status quo.

To be clear, when we speak here of the world – or specific claims to the truth – as socially constructed, we do not mean that we literally create or bring into existence the world when we describe it. Hacking (1999: 10) rather says that we mean that through social construction, we create an *idea of* the world. And these "ideas do not exist in a vacuum" (Hacking 1999: 10). Instead, they inhabit what Hacking (1999: 10) calls a "matrix" – a context in which the "idea

of" is formed, including the individuals falling under the idea, the interaction between the idea and the people, and the manifold social practices and institutions that these interactions involve. So, for instance, as Hacking shows, the matrix in which the "idea of a woman refugee" is constructed is a complex of institutions, advocates, newspaper articles, lawyers, court decisions, and immigration proceedings. Not to mention the material infrastructure, barriers, passports, uniforms, counters at airports, detention centres, and courthouses. These elements are indeed very much material because in their "sheer materiality" they do make a difference to people, to women refugees. Yet, they also constitute the matrix in which the *idea of* a woman refugee, not as one specific individual, but as a certain kind of person, is constituted. And "ideas, thus understood, do matter". In this case, the idea of women refugees constituted within this matrix can after all mean the difference between immigration and deportation. Thus, our theories or descriptions construct experience, not in the sense of bringing it into existence, but by generating a particular idea or understanding of that type of experience. And for Hacking (1999: 11) such an idea, and the matrix within which it is embedded, will influence (even change) the very experience of that experience.

On the second level of the construction metaphor, descriptions and accounts of the world are *themselves* constructed. As Schutz (1962: 5) explains, "all our knowledge of the world, in common-sense as well as in scientific thinking, involves constructs, i.e., a set of abstractions, generalizations, formalizations, idealizations specific to the respective level of thought organization". Strictly speaking there is, then, no such thing as "truth", pure and simple. What counts as "truth" is from the outset selected from a universal context by the activities of our mind. It is always constructed, interpreted. Hence, the era of excessive respect for the truths passed off as "fact" by science has passed. Moreover, in science, "truth" always refers to and is founded upon those constructs already made by the actors within the social reality under study. It is in this sense that Schutz (1962: 6) talks about the thought objects developed by scientists as "constructs of the second degree". The descriptions constructed and used by scientists are, in other words, "constructs of constructs", created upon the creations of actors in the social setting being investigated.

Descriptions of the second degree are constructed by scientists who are real human beings working in real human communities. They are not perfect representations of the external world based on the data automatically turned up by scientists. Instead, descriptions – or theories – are developed by interacting, co-operating scientists influenced by those ideas currently in force. The origin of these ideas that critically modify what scientists see (or are

able to see) is certainly not limited to the conventional realm of science. Ideas can indeed come from any area of human life into science and there prove fruitful in some form or other. As Feyerabend (in Clarke 1996: 32) puts it, "there is no idea, however ancient or absurd, that is not capable of improving our knowledge. The whole history of thought is absorbed into science and is used for improving every single theory". Science as an activity is hereby firmly located as part of the whole matrix of human thought and life.

Indeed, scientific practice is as much about the external world as it is about the human world. Moreover, this human world, as Clarke (1996: 27-32) is quick to point out, delivers a crucial input into the entire scientific process. After all, science does involve a great deal of imaginative research in the human world. And such research always stands in a two-way interactional relation with the development of theory. Theories determine our world view and the focus in our research. In turn, the results of research stimulate the growth of theory, creating the soil in which theories either thrive or wither, but in a far more complex manner than depicted by the mirror metaphor. There is, in fact, no single cumulative effort to uncover *the* truth. In other words, science cannot be described as the systematic discovery of neatly structured facts that exist "in the world". This is but a myth – an ideal view of what scientists have been taught that science ought to be, bearing little relation to the way science is actually practised. Scientific revolutions do not simply build on the work of the past. There is rivalry. Different procedures and theories compete. Some are rejected, others not. Some are helpful, others less so. There is a tearing down as well as a building up. And the upshot of this process, the new paradigm or space of possibilities, is not necessarily predetermined by reason or wisdom (cf. Hacking 1999: 98). What is more, once scientists have identified a particular finding, their work is not complete. While standing by the result, they continue to modify its initial appearance and relationships to other results. This process of continuous self-correction is a quality often missed by accounts of research and science that emphasise the first appearance of "a scientific fact" as though science gets to a result once and for all. Scientists are rather constantly involved in reconstructing and remodelling results, apparatus, methodology, even phenomenology. Thus, far from representing a clearly predictable process of discovery, science (and scientific progress) is in its very essence a human affair, a social process of interaction between scientists and the world they seek to understand.

Scientific theory, then, is *not* the sole repository of a corpus of absolute truth that is gradually being perfected. It is, rather, a particular product of history, of human thought and interaction. There is no way in which the development of scientific theory (and, hence, the establishment

of what counts as "truth") can be separated from the very human fabric of which it is a part. As a result, the theory propounded by scientists is not something dreamed up like a fairy tale with no reference to anything external. Nor is it (as apparently elevated in the mirror metaphor) a simple observation of a single, objectively structured reality independent of all humanness. Instead, scientific theory (as *a* truth) lives (read: is constructed) in the relationship between humanity and the external world (Clarke 1996: 32).

Weighing my options

We are faced with two opposing views on the way in which we come to know the truth – any truth. On the one hand, the mirror metaphor holds that there is one single reality reflected onto a mirror gazed upon by all scientists who then cumulatively produce theories to copy the reflected reality. In the process it is the scientists who, stripped from all subjective elements, determine what reality is "really" like and what can count as truthful statements about this reality. Conversely, the construction metaphor argues that any statement about reality is both constructing reality *and* in itself a construction of reality. In other words, by formulating a theory about reality, about what is true, scientists are not only bringing a version of reality into being and thereby adding to reality, but are also at the same time developing constructions influenced by that reality. In this sense, science is part and parcel of human world of the scientists themselves. This does not mean that scientists remain forever unable to grasp the external world. It does mean that what we do grasp is constructed in and through the relationship between the external world and our own (inevitable) humanity.

I agree with Potter (1996: 98) that there is no sense in trying to decide (on a purely scientific level) whether one of these metaphors is true and the other false. How could such a judgement be made? Potter (1996: 98) says that the difficulty lies in formulating the question. That is, "to judge whether a description was mirroring or constructing reality requires the description to be compared to the reality. Yet reality (or "reality") cannot enter this debate except as another description, which would beg the question of whether this new description is itself descriptive or constructive". Therefore a choice between the mirror and construction metaphors must be based on different considerations. I chose the construction metaphor, based on the following two considerations.

Firstly, I reject the mirror metaphor because of its insistence on eliminating the human (read: subjective) content of scientific practice, which approach is based on its reliance on a flawed

conception of "objectivity". The mirror metaphor polarises objectivity and subjectivity as mutually exclusive properties of the research endeavour, assuming that an "objective mode of inquiry" will necessarily result in the casting of a "truer" image of reality. According to Du Bois (1983: 111), this assumption is strongly reflected in the ways in which "our society has embraced and reified the values of objective knowledge, expertise, neutrality and separateness, and *opposed* them to the values of subjective knowledge, understanding, art, communion, craft and experience". The dichotomies implied by the opposition highlighted by Du Bois are not only endorsed by "our society", but are also commonly upheld within the social research community and the literature it produces.

Yet, according to Mouton (1999: 287), the clash between objectivity and subjectivity rests upon a central mistake incorporated into the mirror metaphor, namely its assertion that "objectivity" refers to a certain state of mind on the part of the researcher. After all, this metaphor holds that "objectivity" can only be achieved once researchers rid themselves of all the notions and ideas which might come between them and a truthful interpretation of the data. Stated differently, "objectivity" in the mirror metaphor, implies "a certain mental or cognitive approach to the 'object' of study" (Mouton 1999: 287). In contrast to this view of objectivity, Mouton (1999: 287) contends that "objectivity" is best understood as a feature *not* of the researcher, but of the research process. "Objective research" therefore means that a study is designed and executed through the application of objective research procedures and techniques in such a way as to maximise validity. Although objective research methods can never guarantee "truth", Mouton (1987: 13-15) maintains that they can lead to closer approximations of truth; that is, to more valid research findings. Thus, as a distinctly methodological value, objectivity refers to a quality of the research process and do not, as implied by the mirror metaphor, demand the eradication of the human influence of the researcher.

Unlike the mirror metaphor and its somewhat flawed perception of objectivity, the construction metaphor recognises the humanness of scientific practice. It is a practice by human scientists, about human actors, in a world that can never be entirely external to all human import. There is no way to avoid this fact. Hence, there can be no reason to omit it from a consideration of the process of truth production or, perhaps more appropriately, truth construction. Taking the human nature of science and truth making seriously may very well afford greater insight, reflected both in and through the theory that is eventually developed.

Secondly, in addition to considerations of a human/humane kind, I opt for the construction metaphor on pragmatic grounds. Here I agree with Potter (1996: 98) that the latter metaphor is likely to be far more productive since it allows a set of questions to be asked that would not make sense had I chosen the mirror metaphor. There is not much that can be done about the reflection in the mirror – the mirror may be cleaned to make sure it is flat and smooth, but this only relates to its passive ability to reflect an image (propounded to be "the truth").

But when I select the construction metaphor and treat descriptions as constructive and constructions, this allows me to visualise such descriptions as houses. Houses are built by people. Some have three chimneys and many windows; others might have no chimneys and a set of French doors. They might be built with concrete, mud, bricks, or glass. They might be very strong or rather delicate. Thus, my "house-like" descriptions would permit me to ask who constructed them, how they were put together, what materials were used, what sorts of things or events were produced by them, and so on.

Having opted for the construction metaphor, I am now in a position to consider a number of questions to clarify the construction of truth: If truth is developed within the relationship between the human scientist and the human world, what can be said about this relationship? What is the nature of the context in which truth is occasioned and situated? And if truth is developed by a human scientist, what are the implications of his or her particular perspective on the construction presented? Can a truth, once constructed, be changed? Moreover, if there is no single reality to be described, is there a limit to the number of different truths that can be constructed? I now turn to an investigation of these questions.

The truth in a relationship

The construction metaphor says that "truth" is no longer located in the external world, in an external concept outside the human Self. It is, instead, to be found within relationships of commitment between the Self and its world. Clarke (1996: 41-42) contends that it is extremely important for us to grasp this relational dynamic, "not as denial of the real presence of the world, but as the means whereby we can continually and creatively engage with that presence" and perhaps come to know it more intimately.

Clarke (1996: 106) supports the emphasis on the importance of gaining greater insight into the essence of a relationship in which truth is constructed by offering an appropriate starting point from which such an inquiry might be directed. He states that the world appears to have been given first and foremost to "my own awareness". The "me" element of this, "my own awareness", introduces the realm of personal consciousness.

To foster a sense of what "consciousness" means, Clarke (1996: 127) encourages the reader to follow an exercise in focused perception or meditation: "Choose an object that you are going to study – a flower or a stone is good, but it should be something that is fairly neutral emotionally. Sit in a comfortable position, with your feet firmly planted on the ground and the object in front of you... In a relaxed state, gently look at your object for ten minutes or so. Don't stare at it, but simply be with it, passively. Don't speculate about it or try to describe it, but be empty and receptive to the object itself".

Clarke (1996: 127-128) then comments: "Most people, when they do this, easily realize that, although there are all sorts of words running through their minds while they look at the object, the words are separate from the awareness of the object... Examining the experience more closely, many people realize that the focus of awareness, so to speak, can be anywhere between the object and the Self... Most importantly, the conscious perception of the flower is, for most of us most of the time, neither rooted purely in the internal conscious mind... nor existing totally independently of our minds... Neither extreme actually reflects our experience, in which there is a mobile focus of awareness involving to different degrees both the external and the internal. Consequently, the conscious perception belongs neither to the Self, nor to the external world independently of Self, but to the relationship between them".

Consciousness, then, *does not* exist in the internal (clearly demarcated) Self somehow hooked up by wires to receive messages from the "real" world. It *cannot* be located in the "unreachable interior of a thinking subject" (Pollio et al. 1997: 4). It *does not* constitute the "private contents of an introspective awareness" (Natanson 1970: 111). Instead, consciousness exists in a relationship, described by Natanson (1970: 112) as a "unity in which the 'subjective' is already in direct connection with the objects of its intentional concern because those 'objects' are parts of the unified structure of the stream of consciousness". In other words, when we meditate on a flower, and observe a variety of types of focus in the experience, we can analyse that variety into a spectrum extending between the two poles of "the Self" and "the flower". But "the Self" and "the flower" are things we abstract from the

experience. The Self and the flower are not given first, and *then* enter into a relationship. Rather, the experience comes first, the analysis second. The relationship *precedes* the terms it is relating (Clarke 1996: 129-130).

It is thus clear that consciousness exists in a relationship. This understanding appears to introduce two important implications. The consciousness vibrating within a relationship is not only destined to be the *consciousness of something*, but also to be the *consciousness of someone*.

Firstly, Merleau-Ponty (1962: xvii) maintains that "all consciousness is consciousness of something". In other words, conscious experience always – necessarily – refer to the object experienced. There is no such thing as "pure" thought, "pure" fear, or "pure" remembrance. Every thought is thought *of*, every fear is fear *of*, and every remembrance is remembrance *of* the object that is thought, feared, or remembered (Schutz 1962: 103). That is, every experience in our stream of consciousness has its reference or direction toward that which is experienced. This recognition, often termed the intentional character of all human experience, reveals our fundamental relatedness to the world in which we live, our basic "being-in-the-world" (Pollio et al. 1997: 7).

Secondly, consciousness is always – inevitably – somebody's consciousness. There is always an I who experiences, whose consciousness must be taken into account. Still, our experience of the I cannot precede our experience of something. Pollio et al. (1997: 8) explain that it appears that we learn and relearn who we are on the basis of our encounters – our relationships – with objects, ideas, and people – in short, with every kind of "otherness". Thus, through our relationships with "otherness", we experience not only the object to which our consciousness is directed, but also the I sitting at the helm of such direction.

So, within the relationship in which consciousness resides there are (at least) two partners involved. On the one hand, there is the very object of experience toward which consciousness is directed, and on the other, there is the I who does the experiencing. The result of this relationship is a *co-constituted* conscious experience. It is specifically "co-constituted", because the character of this experience is acquired neither in the external realm of the "to-be-known" nor in the internal realm of the "knower", but in the animate space between them.

Clarke (1996: 144-146) offers notable insight into the process of co-constitution (or co-construction) through reference to "relational wholeness", a concept borrowed from quantum theory, which denotes the ability of quantum systems to unite into wholes. Thus, "if I am a quantum entity, then when I and another such interact, there is a sense in which, at some level, we are not two but one" (Clarke 1996: 146). Stated differently, when I perceive a flower, this observation constitutes an act of entering into interaction with that flower (or, more accurately, with a part of it). Through this coupling, we become interacting quantum entities that can no longer be regarded as two single (separable) systems. By forming a whole with an aspect of something external, I venture into a system whose inner nature is my consciousness, extended to include the external part. Thus, it is my consciousness that becomes the internal side of a union of part of me and part of the object. I am taking into myself, and experiencing from the inside, an aspect of the external world (Clarke 1996: 146-147).

The process that manifests as "relational wholeness" clearly does not constitute an intellectual episode connecting a thinking subject with a world outside its ken. It is not a passive process of grasping onto something that exists in a given world independent of us. It is a dynamic process of knowing, a quantum event, through which the reality (the truth) of the (previously) external object is to some extent actively created. Its reality now lies in the relational space between us, not in the world independent of us. Clarke (1996: 147-148) also explains that this encounter between me and the object of my experience is heavily weighted in my favour. After all, I bring a powerful filtering system, consisting of all my past memories, concepts and expectations, to bear on the encounter. Consequently, what I experience represents an amalgam of the internal being of that which is experienced (from my inside) and the beings of countless past things experienced that have patterned my consciousness (my hefty filtering system). It is in this way– through relationship – that the external context of the "to-be-known" and the internal context of the "knower" mutually determine (read: *construct*) the conscious experience.

In this section I sought to explain exactly what I mean when I say that truth is constructed in a relationship between a human Self and its world. Following Clarke's guidelines this inquiry set out to consider the notion of "consciousness" which refer to the experience that enters our own awareness through the active engagement between the Self of an I who seeks to know and the object of experience to-be-known. The reality (or truth) of this experience is co-operatively constructed in and through this dynamic relationship. Reality, then, exists in a

relationship. In fact, like Clarke (1996: 128), we might even venture to say that 'reality is relationship'.

The ground, the context, the occasion

The truth of an experience is constructed through and exists in relationship. Such knowing, as a human event, does not and cannot take place in a void. It is unavoidably and irremediably tied to the social setting in which it is situated. It is forever fundamentally rooted (Bittner 1973: 115-116).

Pollio et al. (1997: 13) describes the rootedness of truth construction, of all human experience, in terms of "figure/ground". They contend that "all objects of experience are experienced only in relation to some less clear part of the total situation serving to situate the focal objects. There are no figures by themselves". All figural aspects of an experience emerge against some ground that serves to delineate its specific experiential form (its truth). For this reason, "it is never experientially valid to talk of an isolated figure of experience... we must always talk about the figure/ground structure of experience (note the slash) to emphasize that human experience is a patterned event defined by focal and background aspects" (Pollio et al. 1997: 13).

A different way of saying that "human experience is a patterned event defined by focal and background aspects" is to talk about the "indexicality" (Potter 1996: 43) or "contextual determination" (Douglas 1970: 37) of human experience; more specifically, of the meaning of such experience. The contextual determination of meaning suggests that the reality or "truth" of a human experience, albeit a description, an action, an encounter or whatever, is fundamentally tied to and dependent upon its context. The context is the (only) ground against which a specific human experience can become figural; that is obtain "its specific experiential form" or its truth. An experience can, consequently, only be understood in terms of the context or situation in which it occurs. Potter (1996: 43-44) stresses that "context", as used in this regard, should be understood as more than the gross institutional features of the setting of experience. In fact "context" encompasses *all* the specifics of the situation in which an experience is occasioned; that is, where it fits into and becomes part of a broader social setting and continuity.

If an experience derives its sensibility and warrant from its context (or matrix), the specifics of that context become salient in any attempt to develop a sufficient understanding of the experience. Douglas (1970: 38) considers a number of features that ordains a context with a particular character. For instance these include elements of language, time, space, culture and the like. More importantly, it also includes the knowledge that is taken for granted in the specific setting. And this is where a peculiar problem creeps in. Very often the ground that constructs a specific experiential figure is wholly taken for granted by those involved. Its existence is never doubted or questioned. It is the world where we have our existence, carry on our activities, pursue all our goals. We always take our bearings in this world. We have a certain familiarity with it. And we readily accept it as *simply there*. Of course, in a sense, this is an essential precondition of all human experience and activity (Gurwitsch 1962: 51-52). The unquestioned and unchallenged certainty concerning the world in general underlies, supports, and enters into every particular experience. But there it remains – unheeded, unformulated, unnoted. Consequently, when we explore the meaning of this context, of the ground of a figural experience, we are doomed to both find *and* rely on the taken-for-granted. Thus, a crucial determinant of our exploration into the in-context-meaning-construction of experience is so general that it is virtually unidentifiable. While it is always *simply there*, it remains beyond concrete reach.

Douglas (1970: 30-31) recognises that the ever-elusive taken-for-granted component of a context in which meaning is constructed makes it impossible to do anything more than develop more than a partial understanding of a particular experience. Still, this is an understanding not to be discarded. After all, it does represent a huge improvement on the classic "building-block theory", whereby the meaning of an experience is regarded as entirely independent of the context in which it occurs. Hence, bits of meaning as self-contained wholes (blocks) can be put together (cemented) in accord with certain rules to produce the whole meaning imputed to a concrete (now isolated) experience (Douglas 1970: 37-39). It is assumed, then, that contextual factors can be eliminated without destroying the possibility of scientifically understanding or explaining an experience. Clearly, this approach stands in sharp contrast with one in which the analysis of the contextual determinations of meaning is acknowledged and practised – albeit but partially.

A recognition of the importance of contextual features in the construction of meaning is extremely important, but should never be applied in excess, for then a different danger of distortion looms. While it is crucial to understand the situational nature of human existence,

Douglas (1970: 42) warns that "an overconcentration of the contextual effects to the relative exclusion of trans-situational meanings leads, however inadvertently, to a failure to consider adequately the most crucial aspect of man", which is, "his awesome capacity to transcend himself and his immediate situation". This "crucial aspect of man" means that those involved in a particular context can bring a vast realm of previous experience to bear in constructing meaning within their immediate situation, they can coordinate (or order) their immediate situation with those of many others beyond their immediate grasp, and they can project themselves into an as yet unrealised future. Hence, a consideration of the contextual features that comes into play in constructing meaning should always be complemented by an analysis of the complex relations and interdependencies that exist between contexts and contextual aspects.

Thus, put simply, the "truth" or figural identity of an experience derives from the *combination* of that experience with the specific context or ground in which it is rooted. Accordingly, to understand what an experience means is to have (at least some) insight into the situation in which it occasioned. The development of such insight is seriously complicated by the large portion of taken-for-granted knowledge on which it is built, as well as by the influence of contexts which transcend the immediate. When the significance of these factors is sufficiently appraised, a contextually authentic understanding of (the truth of) an experience becomes possible.

From a perspective

In the beginning of his classic monograph, "A stroll through the worlds of animals and men", the European naturalist Jakob von Uexkull (in Pollio et al. 1997: 3) invited his readers to "blow, in fancy, a soap bubble around each creature to represent its own world, filled with the perceptions it alone knows... Through the bubble we see... the world as it appears to the animal (itself), not as it appears to us. This we may call the *phenomenal world* or the *Self world* of the animal". Von Uexkull went on to suggest that for many scientists these worlds will be invisible because of a prior commitment to conceptualising animal life in purely mechanical terms. He advises us to regard all animals, the human being included, not as machinelike objects, but as subjects who live in their unique worlds that are as "manifold as the animals themselves".

For each of us, our unique world revolves around the Self. In the "Self world", I am "the absolute source" (Merleau-Ponty 1962: viii), for I alone bring into being for myself the world as I see and experience it. Indeed, from the very outset the world – my world – exists for me and forms itself around me. The character (the "truth") of what I see and experience in this world follows from this unique perspective. Stated differently, "all my knowledge of the world, even my scientific knowledge, is gained from my own particular point of view" (Merleau-Ponty 1962: viii). Weber (in Bittner 1973: 118) clearly echoes this notion when he says that "all knowledge... is always knowledge from *particular points of view"* (Weber's italics).

As Schutz (1962: 207) suggests, such a point of view – *my* own point of view – constitutes an essentially subjective position. Its focus is shaped by whatever excites and stimulates my interest. So, when I focus on something and discern its character (its truth) in a particular way, it means that that "something" stands in a particular relation to me, to my Self. It also means that my perspective is always a significant aspect to the character of what is perceived. That is, I am very much part of the ground against which an experience becomes figural – to and for me, and me alone (cf. Pollio et al. 1997: 15).

Taken more broadly, the contention that my perspective is the origin of the reality I discern implies that a person's unique world assumes a particular identity because *someone is seeing it so* (Bittner 1973: 121-122). What is more, the world (and its particular meaning) "could be and probably is altogether different for someone else, because whatever necessity there is in a thing being what it seems to be is wholly contained in the mind of the perceiving subject" (Bittner 1973: 122). Bittner (1973: 123) rightly points out that this does not mean that variously occasioned impressions of the world must be – or even can be – uncritically accepted as the last word concerning the meaning structures (or truth) of the social reality in question. It simply means that what is confronted and related should always be clearly recognised as "someone's social reality". It is affirmed again: "the origin of all reality is subjective" (Schutz 1962: 207).

As true as this contention is for every human being, so it is for the scientist. In the research field the scientist "always sees things from a freely chosen vantage point – chosen, to be sure, from among actually taken vantage points" (Bittner 1973: 122). This vantage point exerts an eminent influence on what the scientist does (or is able to) discern and relate. A recognition of this influence has had one particular ramification worthy of mention here.

Some authors of a notably feminist persuasion (cf. Hartsock 1997: 285-303; Hirschmann 1997: 77-78) urge scientists to assume a specific perspective - not one of bias, but one of deliberate engagement. For them this perspective, called a "standpoint", will produce a more complete and less perverse understanding of the reality being studied. This reality is regarded in terms of a duality. In this duality there is a surface level (or appearance) and a deeper level of reality. The surface level is dominated by privileged perspectives. The degree of privilege granted to such perspectives does not lie so much in their internal criteria of truth, than in the power of the groups in making their standpoint prevail over other equally plausible perspectives. It therefore becomes clear that standpoints (or perspectives) should be judged not only in terms of their epistemological contributions, but also in terms of their position within hierarchical power relations (Collins 1997: 377; Hartsock 1997: 373).

One is reminded that ideas of what knowledge is involve "profoundly important political stakes" (Hartsock 1997: 373). Given this, feminist scientists such as Hundleby (1997: 41) argue that the social research community should consider the influence of dominant perspectives on the type of understanding that is available and should compensate for any such influence by attending to perspectives on the periphery. In accounting for the influence of power differentials on the process of knowledge production, the research community should work to counteract those epistemic roadblocks that prevent politically marginalised perspectives from being articulated and from being heard. Some would even argue that researchers should not merely attend to marginal perspectives – they should indeed assume such a perspective from the subjugated position (from the deeper level). This point of departure would give these researchers an epistemic advantage since they would be able to reveal the inhumanity of the surface level and work to change it (cf. Hartsock 1997: 285-303). It is in this sense that assuming a standpoint becomes a way of knowing - and, for certain feminists, a way of knowing *better*.

Still, as Harding (1986: 148-154) and others (cf. O'Leary 1997: 57; Welton 1997: 15) are quick to point out, there can (never) be *one* perspective, *a* standpoint, from which to launch a challenge on other positions which are presumably more partial and perverse. Even if all perspectives arise from the same level of reality, they are bound to differ because reality (and its construction) is as diverse as the people who populate it. No single standpoint can claim to represent a particular level of reality as a whole. At best, a single position can illuminate certain *aspects* of the social totality. It will always remain but a partial glimpse. There is no one truth, no Archimedean point, no complete position. Indeed, instead of one single totality,

social reality is given to us, to scientist and novice alike, in "complex systems of perspectives" (Schutz 1967: 8).

Once the Archimedean system of knowledge is deconstructed into a shifting, wavering plurality, "a world that can be understood and navigated with the assistance of Archimedes' map of perfect perspectives also disappears" (Harraway in Harding 1986: 193). Perhaps, as Flax (in Harding 1986: 193) puts it, "'reality' can have 'a' structure only from the falsely universalizing perspective of the master. That is, only to the extent that one person or group can dominate the whole, can 'reality' appear to be governed by one set of rules or be constituted by one privileged set of social relationships" or, for that matter, be known from one set of perfectly complete perspectives.

Thus, as long as we refrain from assigning a master over our own experience, or worse yet, from appointing ourselves as masters over the experience of others, our reality, our own soap bubble, will remain bound to the point of view from which it is known. What we know and count as truth from the inside of this bubble – that is, all our knowledge – will emanate from a perspective, from our own perspective – not in singular form, but in abundant plurality. It is against this background that we can conclude with Pollio et al. (1997: 88) that, indeed, "all truth is perspectival".

Openness to change

At this stage of my discussion I have established that the odds are quite slim of arriving at one single, absolute truth, just waiting "out there" for us. I have also established that every truth (or truth claim) is actively constructed (not passively mirrored) in and through a relationship. Within a relationship, the experience that becomes figural for someone from a unique point of view is grounded in a specific context. Now, once constructed, is such a truth static? Should we regard it as forever resting in stationary mode? Or does it show mobility? Is there potential for modification? In short, can a truth (a truthful understanding) change?

Let us consider an example based on the world of fantasy offered by Schutz (1962: 340): "the play world of a little girl, as long as it is undisturbed, is her reality. She is indeed the mother, and her doll her child". Similarly, "in the world of art, that is... of pictorial imagination, knight, death, and devil have 'real' existence as entities within the realm of artistic fantasy.

While the play lasts, Hamlet is to us *really* Hamlet and not Laurence Olivier 'acting the part of' or 'representing' Hamlet". For little children as for the audience of the Shakespearean play, the world which at that moment in time constitutes the focus of their attention is real and true. This is what James (in Schutz 1962: 340) meant when he argued that "each world *whilst it is attended to* is real after its own fashion; only the reality lapses with attention". For James, then, what constitutes a truth at any moment in time is a function of attention.

James (in Pollio et al. 1997: 16-17) regarded a change in our focus of attention as a change in our consciousness. He described this process as "the successive mutations of our field of consciousness". This is a process of more or less gradual change or alteration. Sometimes, the focus alters, and the margin stays. At other times, the focus and margin are modified. At yet different times, abrupt alterations of the whole field may occur. To capture this process of change, movement, fluctuation, and flow, James referred to the "stream of consciousness".

In James' conception the experiences we choose to construct as figural (at any point in time) come and go in a changing, flowing way. As our attention shifts and moves, so too does the experiences to which we ascribe reality. Indeed, our experiences are constantly flowing, "with some parts clear and with other parts serving to provide momentary contexts to support and define the clear central focus" (Pollio et al. 1997: 26). Change, then, is a primary characteristic of our experience – and of our construction of truth.

In addition to change, James' conception of the "stream of consciousness" serves to highlight another distinctive characteristic of our experience and our construction of truth, namely the characteristic of continuity. Continuity means that, while the central events of our experience regularly change, we never loose track of the unity provided by the flow between successive figural events (Pollio et al. 1997: 26-27). Thus, while the stream of consciousness perpetually changes as it encounters different "rock-and-stump-experiences", it remains one stream, unified in and through the single origin from which it flows.

Schutz (1962: 229) wished to emphasise the characteristic of unity and continuity when he spoke of the "finite provinces of meaning" – a term deliberately devised to substitute James' original notion of the "sub-universes" of reality. Through this substitution Schutz (1962: 257) managed to emphasise that the truth of our experiences are not "ontological static entities, objectively existing outside the stream of individual consciousness within which they originate". Indeed, very much *un*like "sub-universes", our experiences on which we bestow an

accent of truth – our finite provinces of meaning – are not separated states of mental life. They do not require some strange transmigration of soul and consciousness alike. They simply denote different tensions (or foci of attention) of one and the same consciousness. In other words, the "finite provinces of meaning" represent one conscious life, flowing uninterruptedly from birth to death, but attended to in different modifications.

The continuously shifting, moving nature of our conscious attention to experience as it transcends from one province of meaning to another holds one important implication for science and scientific description of truth. Schutz (1962: 258-259) hints at this implication when he states that "what formerly seemed to be a reality while attended to may now be measured by another yardstick and prove to be non-real or quasi-real". Note however that this is so only under the specific form of a present non-reality, whose reality may at a later stage be restored. So, what I now regard as the truth of an experience may under a different state of affairs be regarded as a quasi-truth of even a complete non-truth. Obviously, all of this makes experience and the peculiar meaning ascribed to it at this moment in time extremely difficult to describe scientifically. The profound mobility and changability of our moment-to-moment experiences indeed fills our descriptions with ambiguity and uncertainty, sometimes almost intolerably so. This leads Pollio et al. (1997: 27) to conclude wisely that "although we may strive for clarity, we should never be disappointed that our descriptions are more ambiguous than we might hope. Describing the human world on its own terms is at least as demanding as living it in the first place".

Thus, we can conclude that a truth, once constructed, is open to change. In fact, one may even go so far as to regard a truth as but a particular accent assigned to an experience that at a particular moment falls under the gaze of our attention. As the focus of our attention changes, so too does the truthful claim we construct. The potential of such change clearly introduces immense complexity and variability to the process of truth construction. This complexity and variability is only tamed (to some extent, at least) by the unified nature of the stream of individual consciousness. It is one consciousness, one I (or eye) who sees what is finally designated (for that I) as a truth. A truth, then, lies in the eye (or I) of the attentive beholder.

Conclusion

What counts as truth, as a truthful claim to understanding?

The mirror metaphor offers one way of answering this question. This metaphor states that the guiding aim of any study worthy of the name of science should be to see the world of social facts with an unbiased eye. Accordingly, the task of social science can be defined as the simple and accurate description (that is, reflection in language) of life in society. Thus, for a social theory to be regarded as "true", as "worthy of the name of science", it would have to correspond with a simple and accurate description of the social facts of the reality being studied as discerned through an unbiased eye.

A different way of understanding truth is offered by the construction metaphor. In opting for this metaphor, I reject the concept of truth as simply a matter of "accurate" description, of merely reflecting the "reality" as it "really" is by means of the right choice of words and phrases. I think that the sum of all social science theory (including the story which developed as part of this study) does not manage to represent the "closest approximation to the truth", let alone a direct disclosure of it. This would after all presume the existence of an absolute point to which all theory could be compared – an absolute notion of truth I reject.

I therefore believe that all social science theory should be viewed through the perspective of the construction metaphor - as *a human construction* – as a human tale told by one human, about other humans, within a human world. The distinct human presence – and in particular of the researcher's human Self – lends an undeniably human quality to the entire affair of truth construction.

It thus becomes possible to see that the truth which we so eagerly seek to pin down by means of our scientific practices is the product of a dynamic interplay. It is an interplay between two parties, the "to-be-known" and the "knower". The to-be-known is occasioned within a context which supports it in becoming figural to and for the knower. The knower, in turn, discerns the to-be-known from a particular perspective and thus becomes part of the ground that bestows upon the to-be-know its particular figural identity. Together they co-construct and perpetually re-construct not only each other but more importantly, also what eventually becomes "known" as (a) truth.

While this conception of truth construction is not necessarily profoundly novel in itself, the emphasis it places on the human quality of this construction process is significant. The process of truth construction described above indeed reflects a human presence and influence seldom acknowledged openly in the world of science and scientific discovery. Stated more

directly, this concept permits an understanding of the truth (or truthfulness) of every construction, of every story told, as truly lying in the I of the beholder.

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Chapter 6

How is truth developed between two people?

We live in a world in which we are directly involved. Gurwitsch (1970: 39) maintains that our involvement takes shape through our encounters with Others. We live with Others and for Others, orienting our lives to them. We make decisions considering Others, we assume responsibilities affecting them, and we enter commitments embracing them. We join them in common activity and work. We influence them and are, in turn, influenced by them. Schutz (1967: 9) suggests that, in doing all these things, we experience them as Others and understand them as we assume they understand us. In developing such mutual understanding we build a meaningful social world that is as much our world (strictly speaking, my world) as it is the world of Others.

Once again our construction of a meaningful social world – all our social construction of truth – is based on a profound assumption: we readily believe that Others experience their actions as meaningful in quite the same way as we would if we were in their place. We also believe that our interpretations of the meanings of the actions of Others are mostly correct. But Schutz (1967: 9) warns that when such seemingly "common-sense assumptions are uncritically admitted into the apparatus of a science, they have a way of taking their revenge". This danger is particularly acute in the social sciences, because in these sciences we are primarily concerned with the study and the understanding of social phenomena. Hence, an investigation into the construction of meaning or truth between a Self and an Other is clearly of prime importance.

In the intersubjective world…

We have established that for the individual, the Me, the world in which I was born and am living in revolves around Me. I am the centre, the null point, toward which the world is oriented. That is to say, this world has significance and meaning first of all by Me and for Me. But I share this world with Others. How, then, to understand this world which we share with Others and which we assume they share in much the same way with us?

Schutz (1962: 133; 1967: 8-10) describes this world as an "intersubjective" one. It is the public world with which we are very familiar, irrespective of what science may teach us. It is the world within which "we pursue all our goals and carry on all our activities, including scientific ones. As the universal scene of our life, the soil, so to speak, upon which all human activities, productions, and creations take place, the world of common experience provides the foundation of the latter as well as of whatever might result from them" (Gurwitsch 1970: 35).

But why should this common world be called 'intersubjective' and what does it mean for the construction of truth – one of the human products – that takes place within its confines?

… a world of encountering

From the very outset the everyday world is "intersubjective" because it is the locus of every encounter with an Other, with "Thou" (Natanson 1970: 103). In Schutz's words (1962: 133), it is the world "we live in… as men among other men, bound to them through common influence and work, understanding Others and being an object of understanding for Others". Through every encounter with an Other the intersubjective world is revealed in its very essence; not as "mine" but as "ours"; not as private, but as public (Natanson 1970: 103-104).

In our intersubjective world we engage and interact. We live in what Schutz calls a "We-relationship" (1962: 15). This relationship, which involves a mutual interplay of communicative action and reaction, is based on the co-presence of two parties – Schutz (1962: 16) calls them "consociates" – who in the vivid present share a community of time and space. To share a community of time means that "each partner participates in the on-rolling life of the other, can grasp in a vivid present the other's thoughts as they are built up step by step" (Schutz 1962: 16-17). To share a community of space implies that 'a certain sector of the outer world is equally within the reach of each partner, and contains objects of common interest and relevance (Schutz 1962: 16-17). So, as long as the We-relationship lasts and their biographies intertwine, consociates partake in one another's lives and understands one another's thoughts, fears, plans, and hopes. "Here and here alone," Gurwitsch (1962: 65) maintains, "do the partners grasp one another in their unique individuality; do the Selves of the consociates mutually reveal themselves… according to the lesser or greater degree of intimacy in their relation". No other social relationship exhibits these distinctive features through which

the We-relationship acquires the quality of a meeting in the intersubjective world of unique individuals as complete totalities.

Thus, in the intersubjective world, I encounter you, as the Other. Here I am able to grasp your subjective experiences. I can do so only to the extent that we are mutually involved in an existing We-relationship, for it is only in this face-to-face relationship that I can concretely experience you at a particular moment in your life. In Schutz's (1967: 167) words, "I live in your subjective meaning-contexts only to the extent that I directly experience you within an actualized context-filled We-relationship". My experiences of you and my resulting understanding of your subjective experiences are directly related to the nature (the intimacy, the actuality) of the relationship we share in the vivid present.

But although our relationship has content and is real, it is never complete. Although your unique individuality is revealed to some extent, it is never fully accessible to me. Our biographies, although intertwined, never become one. Our involvement, although genuine, never allows our lives to be lived by one another. While the total continuum of all the experiences I have lived through is, at least in principle, at all times open to me, the same is not true for your, the Other's, continuum of experiences. As Schutz (1967: 105-106) explains, "your stream of lived experiences is also a continuum, but I catch sight of only disconnected segments of it... If I could be aware of your whole experience, you and I would be the same person". But now I know only part, certain aspects, of you, the Other. Natanson (1970: 110) puts it more eloquently, 'although the Thou is given as a person, the mode of givenness is essentially adumbrated. Some aspects of the Other are manifest; Others are presented in shadowy form or are completely opaque".

Thus, my experience of you falls far short of your whole experience of you. Your experience can never be entirely open nor directly revealed to me. This is simply not possible as we are two persons, not one. Hence, what is given to me is something which I must interpret.

... a world of understanding

The intersubjective world that we share with Others is unequivocally a world of meaning and understanding. It is, Schutz (1962: 133) maintains, "a universe of significations to us, i.e., a framework of meaning... which we have to interpret". In this world that we share I not only

engage with you, the Other, in a face-to-face relationship, but also attempt to understand you and your experiences.

Through every act of understanding I develop a context or configuration of meaning to which my lived experiences of you belong. That is, I arrange what I experience of you within my own meaning-contexts. But my contexts do not necessarily agree with yours. As Schutz (1967: 105-106) explains, "you and I differ from each other not merely with respect to how much of each other's lived experiences we can observe. We also differ in this: When I become aware of a segment of your lived experience, I arrange what I see within my own meaning-context. But meanwhile you have arranged it in yours. Thus, I am always interpreting your lived experiences from my own standpoint. Even if I had ideal knowledge of all your meaning-contexts at a given moment and so were able to arrange your whole supply of experience, I should still not be able to determine whether the particular meaning-contexts of yours in which I arranged your lived experiences were the same as those which you were using. This is because your manner of attending to your experiences would be different from my manner of attending to them". So, how I interpret my experiences of you do not necessarily correspond with your interpretation of your experiences – because we differ and because we do not look at it from the same point of view.

More specifically our interpretations do not correspond because the contexts of meaning I develop of your experiences are heavily weighted in my favour. The reason is that when I interpret my lived experiences of you into particular contexts of meaning, I bring a highly structured background of meaning to bear (Schutz 1967: 23-34). In fact, I bring a whole baggage of Self along as I enter into every encounter with an Other – including specifically my stock of knowledge, my biographical situation, and my choice of interests.

My stock of knowledge at hand

To every We-relationship in which I enter with an Other, I bring what Schutz (1962: 7) calls my "stock of knowledge at hand". The latter consists of all the acquisitions of knowledge and experience I possess at any one moment. More specifically, Schutz's conception of the "stock of knowledge at hand" includes "the language, the multiple typifications embodied in language, the recipes of all sorts, the rules for handling and manipulating things, the modes of conduct, behavior and actions in typical situations" (Gurwitsch 1962: 56-57) – in fact, all my knowledge of the world in which I live, to which I respond and which responds to me.

My stock of knowledge at hand is largely socially derived. In other words, it comprises what has been passed on to me by those who taught me and whose teaching I accepted on the strength of their authority as well as what I have acquired through intercourse with my fellow Others (Gurwitsch 1970: 49-50). As the bulk of my stock of knowledge at hand is handed down to me through society, only a very small part of it originates within my personal experience. Gurwitsch (1962: 57) goes so far as to argue that "all my personal acquisitions presuppose some socially derived 'stock of knowledge at hand' inasmuch as they are inserted into and have to find their place within this socially derived setting". According to this view no personal acquisition, however it is arrived at, can ever be regarded as an isolated event.

My stock of knowledge at hand is not only predominantly socially derived; it is also largely socially approved. Gurwitsch (1970: 49-50) explains that this does not imply any "explicit promulgation, nor any kind of legal or formal sanction, but rather the fact that in a given society certain modes of conduct are tacitly and as a matter of course accepted and taken for granted as behavior appropriate... in typical situations". To a very significant extent my stock of knowledge at hand will therefore reflect the nature of the particular society in and through which it has been acquired. It is in this respect that Flick (1994: 180) speaks of the "*conventionalization* of knowledge and thinking".

My stock of knowledge at hand can never be a completed entity in itself. As long as my life goes on, so too will my stock of knowledge grow and enlarge (Gurwitsch 1962: 56-57). As it does so, it forever serves to shape my interaction and acts of understanding within the intersubjective world. Schutz (1962: 7) indeed maintains that all interpretation in this world is based on a stock of previous experiences of it, with these experiences in the form of "knowledge at hand" functioning as a scheme of reference for me. My stock of knowledge at hand becomes, then, the "conceptual eyes" (Natanson 1970: 120) through which I see, interpret, and come to understand my world.

Thus, within the bounds of a face-to-face relationship with an Other, my stock of knowledge at hand encompasses both the general (socially derived) knowledge I have of what another person is, as well as any specific (personally acquired) knowledge I may have of that particular Other. As our relationship unfolds from moment to moment, so too my knowledge of the Other and his or her experiences will be questioned and confirmed, advanced and sedimented. Throughout this process of understanding, my stock of knowledge at hand will direct the development of my interpretation (my "truth") of the Other and his or her experiences.

My biographical situation

Along with my stock of knowledge at hand, I bring to every We-relationship I enter my own "biographical situation" (Schutz 1962: 312). This situation, in which I find myself at every moment of my existence, is unique to me. It is "given to me, and to me alone" (Gurwitsch 1962: 60). I do not – cannot – share it with anyone.

Schutz (1962: 312) argues that by its very nature this unique situation is "biographically determined". That is to say, it has its own history. On the one hand, its history derives from the sedimentation of all my previous experiences and, like my stock of knowledge at hand, develops in continuity with these experiences of my past as long as I live. On the other hand, my personal history constitutes only a small part of my biographical situation. My situation is part of and defined by the broader historically given world which existed before my birth and which will continue to exist after my death. In and through this historically given world my fellow Others become elements of my own situation, and I of theirs.

Schutz (1962: 312) goes on to explain that my biographical situation is centred around the actual "Here and Now". The latter denotes the full concreteness of my existence in my particular environment. The nature of this environment is largely defined by the specific cultural group, the society, and the period of history into which I was born and now find myself. Gurwitsch (1970: 39-40) rightly stresses that what is important here is not the mere cultural, social, and historical facts of my existence as they might viewed by some impartial observer, but how these elements appear, enter and define my situation. For my situation directly influences the outlook I have and the understanding I (am able to) develop of those Others whom I encounter in this environment.

Furthermore, I do not simply belong to my particular environment, but occupy a certain place and position within the actual Here and Now of my biographical situation. Schutz (1962: 9) explains that this is not merely a position in terms of physical space and outer time or of status and role within the social system, but also a moral and ideological position. According to Gurwitsch (1962: 60) the fact that I occupy my present position is "the result of the whole history of my life. It is due to the circumstances… which in the course of my personal history have contributed toward making me become what I am". From the unique vantage point that my biographical situation offers me, I perceive and reach understanding of my world.

Thus, through the historical world we share, every Other I meet in a face-to-face relationship enters into and becomes part of my unique biographical situation. The unique environment of my biographical situation, together with the integral position I occupy within it, presents me with a particular way of perceiving the Other. Thus, as does my stock of knowledge at hand, my unique biographical situation turns into a pair of conceptual eyes, a pair of lenses I put on whenever I meet an Other. In this way, my unique biographical situation in its totality defines the understanding (the "truth") I am able to develop of the particular Other.

My choice of interest

Schutz (1962: 9, 208, 283, 284) highlights one last feature that I bring along with me as I enter any face-to-face relationship with an Other. He variously refers to this feature as my "interest" or "relevance", my "purpose at hand" or "pragmatic motive".

He uses each of these terms to emphasise that, in any face-to-face encounter with an Other, I select from the multitudinous characteristics present in that experience only certain peculiar ones that appeal to me. For one reason or another, the selected characteristics seem to me to be relevant to the sum total of my situation in a given experience. Schutz (1962: 283-284) contends that this process of selection is chiefly governed by my interest. This "interest" is never an isolated instance, but rather exists within a loosely organised system of interests that is always open to change from encounter to encounter.

Elaborating on Schutz's concept of interest, Heeren (1970: 47-48) stresses that in selecting certain features as of more interest than others in a particular encounter, I am making a personal choice. I choose among the disparate array of actual and potential features only those that are important to my own interest. As I make this choice I accentuate certain issues, I highlight what is significant for me, I identify what I regard as problematic, I indicate what I assume may be taken for granted. This structure, created by my "interest", organises my understanding. My understanding, then, does not stand independently of my interest. On the contrary, my understanding of the Other and his or her experiences is (at least to me) a matter of decidedly practical importance (Bittner 1973: 110). Indeed, as Schutz (1962: 208) puts it, my encounter with an Other is very much subject to the governance of my "pragmatic motive", to the rule of my interest. Consequently the structure and content of my understanding must be assumed to be determined by my interest at hand, at least to a very important extent.

Thus, my experience within a face-to-face relationship with an Other closely matches the interest I deem of relevance in such an encounter. This means that the understanding or the "truth" of the Other that I may develop – based on what I attend to in detail, what I identify as worthy of further pursuit, or what I simply take for granted – will very much reflect my choice of interest at hand. In a word, what I see and understand will be what my interest prompts me to see and understand.

The difference between my understanding of your experiences and your understanding of your experiences is no longer limited to the disparate degree to which your lived experiences are available for both of us to see. It is no longer just what we see that makes the difference; it is also how we see. That is to say, the difference between the understandings we develop is, aside from what we see, also fundamentally related to the ways in which we see. And we see differently. The entirety of your lived experiences is open to you and so too the interpretation of their meaning for you. But for me there is no way to simply intuit the subjective meaning of your experiences. Hence, I am left to interpret my lived experiences of you. And when I do so, I bring my entire Self – my stock of knowledge at hand, my biographical situation, my choice of interest – to bear on every aspect of that interpretation. So my entire Self leads me to see and understand you in a different way than you might do yourself.

What is more, I see (and understand) differently than you do, without even noticing it. This is possible because "in the living intentionality" of the We-relationship that we share, "I 'understand' you without necessarily paying any attention to the acts of understanding themselves. This is because, since I live in the same world as you, I live in the acts of understanding you. You and your subjective experiences are not only... open to my interpretation, but are taken for granted by me together with your existence and personal characteristics". Thus, "while I am directly experiencing you and talking with you, the whole complicated substructure of my own interpretation of you escapes my attention" (Schutz 1967: 140-141). Living in the We-relationship I do not attend to nor reflect upon my own experiences or awarenesses. I simply live through the relationship. The result is that I am incomparably better attuned to you, the Other, than I am to myself.

The contribution of the Self to understanding an Other, while it usually lurks beyond conscious awareness and is only accessible in retrospect, may be forced into the realm of consciousness if I should choose to do so. I can bring my process of interpretation, all my acts of understanding, within the focus of my gaze at any moment. For instance, I may choose to

check my interpretations and ask, 'Have I understood you correctly?" "Don't you mean something else?" "What do you mean by such and such action?" These are, as Schutz (1967: 141) recognises, typical of the questions I ask and am indeed forced to ask every day in my relations with other people. The moment I raise such questions, "I have abandoned my simple and direct awareness of the other person, my immediate grasp of him in his subjective particularity. I have abandoned the living intentionality of our confrontation. The light in which I am looking at him is now a different one: my attention has shifted to those deeper layers that up to now had been unobserved and taken for granted. I no longer experience my fellow man in the sense of sharing his life with him; instead I 'think about him'". It is only within the We-relationship that such questions are possible and make sense because it is only within this relationship that I and the Other share an actual concrete co-presence. Furthermore, in the process of verifying, clarifying and correcting my interpretation of the Other's subjective experiences, I have the valuable opportunity to expand and enrich my understanding of the Other. In fact, Schutz (1967: 171) posits that "this becoming-aware of the correctness or incorrectness of my understanding of you is a higher level of the We-relationship. On this level, I enrich not only my experience of you but of other people generally". So it is that in becoming aware of how I – the Self – understand, I substantially improve and promote a better understanding of the Other, both specifically and generally.

Thus, in the intersubjective world of meaning, I am forever seeking to understand you, the Other. In the process, I develop meaning-contexts to which my lived experiences of you belong. These meaning-contexts of your experiences can never wholly correspond with the meaning-contexts that your develop of your own lived experiences exactly because we see differently. We see differently because my way of seeing, of interpreting and understanding, falls under the direct influence of my entire Self. Although my Self can at any moment be brought under the spotlight and be opened to verification, its contribution can never be erased. Rather, a closer look into the ways I see will allow me to see even better.

My claim to understanding?

Bearing in mind all that has now been said, what can I claim about the understanding (the 'truth') I develop within a We-relationship with an Other about his or her experiences?

Far from claiming anything, I must rather confess that my understanding of the Other is incomplete. This is because the understanding that I am able to develop of you and your experiences is largely based on my own subjective experience of you as the specific Other I encounter in the concrete, unfolding face-to-face relationship we share. Hence, I cannot but agree with Schutz (1967: 106) that "everything I know about your conscious life is really based on my knowledge of my own lived experiences".

If I accept that everything I understand about you is based on my experience of you (and not your experience directly related to me), what does this mean for the social research context?

The conception of how I come to understand the experiences of an Other within a face-to-face encounter implies that the researcher cannot, under any circumstances, seize the living actuality of the Other's experience. Your Here and Now is completely unique to you. Your stock of knowledge is built up and utilised from your unique biographical position and through your choice of interest alone. As a researcher, I can share a great deal with you in the We-relationship. I can share a certain dimension of time and space with you in the vivid present. Nevertheless, even in the immediacy of the We-relationship, I do not "become" you nor do I mysteriously enter your lived experience. As Natanson (1970: 113) puts it, "sharing is not invading". Therefore the researcher can never claim to enter directly into the actuality of an Other's world.

Furthermore, as the researcher, I interpret. This alone suggests that all interpretive understanding transpires through my mind *and* that all such understanding is transposed in the process. This fact can only *not* matter if we assume that the researcher's mind, my mind, is completely purged of all subjective interests, preconceptions, values, and the like. But this is of course simply impossible. There can be no complete detachment from all local circumstances in order to discover some "objective" meaning. There is no "mental tabula rasa" (Arbib & Hesse 1986: 176) through which I can approach a human situation. The Self of the researcher cannot be eliminated from his or her perspective of the Other. To assume that this might be possible would be to assume that a "neutral" perspective on the side of the researcher is a feasible epistemological goal. Yet, the attainment of this goal would in effect require the researcher to view the Other from a "perspective that is no perspective at all" (Gadamer in Pollio et al. 1997: 45). Thus, to understand does not produce some elevated (prejudice-free, Self-free) understanding of an Other, but rather remains (perhaps notoriously so) dependent on the researcher's own circumstances (Arbib & Hesse 1976: 176).

Within the research context, this critical point implies that the "truth" – that is, the understanding – that I construct is significantly influenced by my experience and interpretation of the occurrences which constitute it. As Stanley and Wise (1993: 159 – 160) state, "it isn't possible to do research... in such a way that we can separate ourselves from experiencing what we experience as people (as researchers) involved in the situation". This appears to closely correspond to Morgan's (1983a: 13; 1983b: 369) view that what is observed and discovered about a particular research field is as much a function of the ways in which the researcher engages with the particular phenomenon of interest as it is of the phenomenon itself. Thus, my construction of an understanding cannot be separated from the potentially significant influence of my personal involvement within and experience of the research context.

A recognition of the researcher's personal contribution to the construction of social theory represents a cornerstone of the feminist tradition. Within this tradition, it is asserted that "all research necessarily comes to us through the active and central involvement of researchers" (Stanley & Wise 1983: 196). To argue otherwise would merely perpetuate the misleading image of the social researcher "as the objective observer of fixed reality, the neutral seeker after an external and objectifiable truth" (Du Bois 1983: 112). Stanley and Wise (1993: 114) trace the origin of this conception of the researcher to "the mythology of 'hygienic research'" in which the researcher can be "there" without having any greater involvement than simple presence.

In contrast with the "hygienic research" approach, feminism regards the researcher as "the medium" (Stanley & Wise 1993: 157) through which all research occurs. It strongly rejects the notion of '"the researcher' as a god-like creature who is able to leave behind subjective involvements while conducting research" (Stanley & Wise 1993; 113). Feminism thus firmly embraces the researcher's subjectivity and renounces any attempt by a researcher to withdraw from the social reality under investigation to a position of attempted neutrality and objectivity. I, the researcher, am instead urged to acknowledge that the entire process of social inquiry is rooted in and expressive of my Self and my subjectivity (Du Bois 1983: 112).

In this context subjectivity refers to Schutz's conception of the highly structured background of meaning that a researcher brings to bear when interpreting the lived experiences of an Other. In other words, when I interpret my experiences of you, I bring a whole baggage of Self along, including my stock of knowledge, my biographical situation and my choice of interest. Adler and Adler (1987: 84-86) contend that those researchers who learn to draw more

directly and consciously on this complex and multifaceted Self may achieve the closest possible understanding of the phenomenon being studied. Indeed, Duelli Klein (1983: 95) writes that such researchers may be able to "produce a kind of scholarship that encompasses the complexity of reality better than the usual fragmented approach to knowledge".

This argument, as proposed by both Adler and Adler and Duelli Klein, appears to be supported by the research experiences reported by some researchers. Referring to his study on loneliness, Moustakas (1981: 210-213) explains how he had immersed himself into this phenomenon in order to gain a truly comprehensive understanding of loneliness: "I was certainly not studying loneliness simply as an intellectual or academic question, in a detached manner, but rather in an integrative, living form; becoming part of the lonely experiences of others; being within lonely moments in living; being involved, committed, interested, concerned, while at the same time aware of an emerging pattern and relatedness... I steeped myself in a world of loneliness, letting my life take root and unfold in it, letting its dimensions and meanings and forms evolve its own timetable and dynamics" (Moustakas 1981: 212-213).

Moustakas' powerful research experience – and in particular his use of the Self – supports Polanyi's (in Moustakas 1981: 211) claim that "into every act of knowing there enters a passionate contribution of the person knowing what is known," and that "this coefficient is no mere imperfection but a vital component of his knowledge". This again places my Self central within the research process and, according to Collins (1986: S29-S30), legitimates my subjective experience of this process as an important and valid way of knowing.

As a way of knowing, my complex subjectivity guides me throughout the process of social inquiry. Peshkin (1984: 277) argues that although my subjectivity does not blind me to perspectives other than those following naturally from my subjectivity, these other perspectives are not reinforced by my personal dispositions and, hence, fail to get the same attention as those that are. The discarded perspectives are therefore neither explained and connected to other aspects of the phenomenon being studied, nor expanded so that the promise of each perspective is most fully exploited.

As a result, the researcher feels drawn to tell a particular "story"; that is, to present a particular construction of the social reality under investigation. This story – as "the gift of my subjectivity" (Peshkin 1984: 278) – is borne out of facts that are potentially available to any other researcher. The researcher does not therefore practice an "untamed subjectivity"

(Peshkin 1988: 21) as this would contain the potential of easily degenerating into subjectivism. Such a practice would, as Peshkin (1984: 280) shows, also leave no scope for verifying the researcher's perceptions and interpretations by the generally accessible experience of other investigators. Founded in my particular perception and ordering of the facts, I relate the story that best follows my construction of the research setting. Peshkin (1984: 278) asserts that this neither implies a rejection of other possible stories or competing accounts of reality nor an assertion that the chosen story is somehow the best or "truest" story to be told. Instead, it simply lends support to Morgan's (1983b: 369) view that the same research field is capable of yielding many different "kinds of knowledges" or stories (cf. Heaphy 1998: 26-27 for a similar view).

The failure to exploit fully themes other than the one the researcher has chosen may be seen as a shortcoming, but Peshkin (1984: 278) sees it as "the reality of social research conducted in complex settings". Peshkin explains this view by noting that complex research settings "support many stories, so to speak, not all of which can be told – or told most effectively – by any one researcher". Morgan (1983b: 369) indeed shows that a single researcher is often only able to realise one possible story within a much wider set of possibilities. In the light of this, Peshkin regards the researcher's subjectivity as simultaneously enabling and disabling as it impels the researcher to entertain and develop some research possibilities while it restrains and delimits the researcher from developing others. The researcher's subjective involvement therefore exerts a substantial influence on both the process and the product of a particular study.

In my role as social researcher I must therefore recognise that there is no privileged way of understanding the experiences of the Other. I cannot enter and relive the Other's experiences, because I am not the Other. I cannot adopt the Other's perspective, because my perspective is firmly rooted in my own being. To do away with my own perspective would be to do away with myself. This would not allow any insight at all because my only way of knowing and understanding anything about the Other is through my own Self.

Conclusion

Indulge with me, for a moment, in a simple fantasy…

Picture in your mind that, in the intersubjective world we share, you and I are now entering a face-to-face relationship. You are the Other whom I, the researcher, long to understand. As you are speaking to me, you are building up the experience that you want to convey to me, step by step, adding word to word, sentence to sentence. As you speak, I am listening to what you are saying to me. Both of us experience the ongoing process in a vivid present. I literally see you in front of me. I hear your words. I watch your face and gestures and listen to the tone of your voice. As I do, I become aware of much more than what is directly communicated to me through your words alone. I am in pace with you and my interpretative actions follow every moment of my lived experience of you as it transpires through our relationship. To the extent that you and I mutually experience this simultaneity, growing older together during this period of time, sharing this particular space, living in it together, to *that* extent alone can I develop some understanding of the subjective meaning of your experiences.

In our immediate relationship I will never grasp your lived experiences in their entirety. My insight and understanding will forever be limited as I, a human being, cannot relive your experiences nor adopt your unique perspective, the contexts of meaning to which your experiences belong. What does fall within my human reach is to interpret what is revealed to me. That is, I can develop my own contexts of meaning into which I can then fit my lived experiences of you. These contexts reflect *my* experience of you, *not* your experiences of yourself. They reflect the way in which *I* see you, *not* how you see yourself. In essence, then, what transpires for me, what I come to understand about you and your subjective experiences, reflects me and the substantial contribution of my Self to my experience of you in and through our relationship.

Thus, the researcher's Self and the relationship into which that Self enters in order to understand the Other must undoubtedly be recognised as one of the most – if not *the* most - significant horizons by which the human construction of "truth" is to be understood. It thus becomes imperative to "force" the researcher's acts of understanding into the realm of conscious awareness and reflection. This will not only expose the deeper (previously taken-for-granted) layers of understanding where the researcher's Self and subjectivity makes its most direct contribution, but is also likely to enrich the understanding (the "truth") that the researcher is able to construct of the Other.

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Chapter 7

How can truth be evaluated?

Thus far we have established that "truth" is, in its very essence, a *human* construction, by a *human* researcher, working within a *human* world. Having said this, we cannot but immediately wonder about the actual truth-value of any human understanding of an Other's experiences. What is the truth-value of our knowledge claims about an Other's experiences?

Does not such a categorical recognition of the central standing of humanness and, more specifically, of the contribution of the researcher's Self, suggest that all human understanding is inevitably doomed to be nothing but wholly subjective (read: biased), only to be reached through some esoteric, haphazard method of intuition (Natanson 1970: 112-114)? Moreover, does this recognition not directly invite the danger of only finding in the Other what we already expect to be there? Every interpreter does, after all, have a set of knowledge, a set of concepts at his or her fingertips. Such a conceptual system may be entirely necessary if we are to go about our work scientifically. But, as May (in Pollio et al. 1997: 44) asks, "how can we be certain that our system, admirable and beautifully wrought as it may be, has anything to do with a specific Mr. Jones, a living, immediate reality sitting opposite... us in the consulting room? May not this particular person require another system, another quite different frame of reference?"

Clearly, the danger here is that the concrete human being sitting opposite me will be replaced by some artificial creation of my system of thought, that a meaningful understanding of this Mr. Jones will slip through my fingertips exactly to the extent that it displays but my own fingerprints. In short, does the recognition that an understanding of the Other is a *human* product bearing the imprints of its *human* producer require, as Harding (1986: 137) asks, "the exaltation of relativist subjectivity"? Are we now left to assume that all forms of *human* understanding are equally justifiable, and equally deficient?

This serious concern points to the fact that the social construction is often accompanied by (or at least placed in the company of) "a great fear of relativism" (Hacking 1999: 4). This fear stems from the use of the metaphor of construction as a means of arguing that scientific results, even in fundamental physics, are "social constructs". For instance, a book entitled "The social construction of anorexia" might appear as a work which argues that the suffering of these

patients are exaggerated and their symptoms but mere fictions. No one would want the notion of relativism to dictate to us that such a work will, as far as it concerns "truth", be on par with all others.

Hence, it becomes critical to evaluate the truth claims of the different understandings that we as researchers develop of an Other's experiences. The remainder of this chapter is devoted to finding ways of making such an evaluation both credible and practical within the social research context.

Freeing our knowledge

The truth-value of different understandings can (and do!) differ. What we must do is find a way of discerning the truth-value of a particular understanding. To do so, we must make the *human* producer – the Self – and its particular *human* production – an understanding, a truth – more accessible to the scrutiny of anyone who cares to make the effort. We must, in a word, free our knowledge (Douglas 1970: 28).

As I use the term here a freeing of our knowledge is *not* equivalent to following the road once so forcefully decreed by objectivity. According to the discussion by Bittner (1973: 111) and Douglas (1970: 25), objectivity demanded that for knowledge to be truly free, it must be free of the knowing subject, the human mind. Hence, it required a set of formalised procedures that was supposedly able to externalise and eliminate all effects of that knowing mind on the understanding gained. The knowing mind was after all, so it was believed, capable of grasping the "thing in itself". If the "thing it itself" was then placed within a pure realm of universal co-ordinates any knowing mind would be able to grasp or know it independently of the concrete situation in which it was originally known or in which the knower grasped it at a particular time. Such understanding or knowledge was absolute – "it was absolutely objective" (Douglas 1970: 25).

In accordance with the objectivist theory of knowledge, all subjective experience of social meanings should be transformed into objective (absolute), externally perceivable events. Douglas (1970: 26) suggests that many scientists realised that this ad hoc construction of evidence, "this treatment of objective (hard) measurements *as if* they were independent of common-sense understandings of everyday life", was just that: *as if*. Still, they recoiled from

this conclusion and continued to insist upon the merit of the objectivist theory. They became what Douglas (1970: 24) calls "insincere" scientists who constructed ad hoc theories and acted *as if* they were true, absolute and objective.

Clearly, any recognition that knowledge of Others is grounded in the *human* world and produced by *human* scientists, cannot but refute even the slightest possibility of such an absolutist, objectivist conception of human understanding that will turn social science into an "*as if* science" (Douglas 1970: 26). For Bittner (1973: 114-117), the ideal of absolute objectivity is now exposed as unattainable, not to mention entirely inappropriate to the study of infinitely complex social realities.

If it is agreed that the bright promise of a formalistically regulated objectivity is not to be, how else can we free our knowledge and thereby make our Selves and our understanding more accessible to outside scrutiny?

A more meaningful alternative to objectivity should be based on a forthright recognition of research as a process that occurs through the medium of a person – the researcher – who is always and inevitably present in the research context. Based on such a recognition, researchers could then be encouraged to "come out", thereby making the centrality of the researcher in all research processes explicit (Stanley & Wise 1983: 197).

Stanley and Wise (1983: 197) note that it has been suggested that an approach which encourages researchers to "open up" and "come out" and which makes them "vulnerable" to scrutiny is nothing more than "mere self-indulgence" and will, as Rosaldo (in Barbour & Huby 1998: 5) suggests, only result in the menace of "essays laced with trendy amalgams of continental philosophy and autobiographical snippets". In their reaction to this suggestion, Stanley and Wise argue that it may indeed be "self-indulgent" to do anything other than what they propose. They maintain that "most social science research... has been riddled with the self-indulgences of people who have refused to face up squarely to their own active involvement within the central processes of constructing research" (Stanley & Wise 1983: 197). In contrast, the alternative which Stanley and Wise (1983: 197) advance, and to which I will refer to as the practice of critical reflection, represents "no easy, sloppy or self-involved exercise in relating inner thoughts, feelings and fantasies. It involves us in a disciplinary, scholarly and rigorous explication of the bases of our knowledge by tying in such an explication to a detailed analysis of the contexts in which such knowledge is generated".

In support of Stanley and Wise's approach, Morgan (1983b: 374) contends that such an open and critical explication and analysis of the research process, will ideally "reorient the role of the researcher from that of a technical functionary pursuing a pre-specified form of knowledge... and place responsibility for the... research directly with the researcher. Each researcher would carry an obligation to reflect on the nature of his or her activity as a means of choosing an appropriate path of action". Morgan strongly encourages and indeed expects each researcher to assume responsibility for critically reflecting upon the particular context within which and activities through which the research process passes. It is only when this approach has been adopted that researchers will be able to truly come to grips with the historical and social nature of their own intellectual products.

However, in advocating the practice of critical reflection as a means of freeing our knowledge we should be wary of not making the same mistake as the absolutist scientists. They see this "freeing" as an absolute freeing and then act *as if* they had achieved this goal (Douglas 1970: 28). It is clear that it is impossible to ever completely rationalise, let alone to eliminate, the infinite number of possible contingencies within a social (read: human) research setting. Thus, freeing our knowledge can only be relative – progressive yes, but still relative.

Practical steps – towards critical reflection

Based on the contributions of both Morgan (1983b: 374-375) and Stanley and Wise (1993: 159-166), the practice advocated here requires researchers to critically reflect, firstly, on their own contribution within the research context; secondly, on the dynamic nature of their relationship with the researched; and thirdly, on the nature and implications of the strategies they employ within the research process.

The researcher's contribution

I have established that the specific understanding or "truth" that a researcher constructs is directly influenced by the highly structured background of meaning which he or she brings to the research context. Freeing our knowledge through the practice of critical reflection first and foremost encourages researchers to develop a greater awareness of their own contribution within the research process.

This implies a continuous consideration of the ways in which the researcher's Self and subjectivity affect the data that is gathered and the picture of the social world that is produced (Reay 1996: 60; Bittner 1973: 118). After all, behind the researcher's Self lies a multiple personal disposition – the result, as Peshkin (1984: 270) explains, of the amalgam of the researcher's class, race, status, gender, and value orientations, that may in numerous ways be engaged by the realities of the research situation. Researchers should therefore remain meaningfully attentive to the nature and implications of their own contribution throughout the course of a particular study and, that is, "not retrospectively when the data have been collected and the analysis is complete, but while their research is actively in progress" (Peshkin 1988: 17). According to Berg (1984: 227) and Peshkin (1988: 17), such a practice of critical reflection is likely to promote a greater understanding of the phenomenon of interest by providing additional kinds of data which may, in turn, suggest supplementary avenues of inquiry.

Bordieu (in Reay 1996: 61) importantly notes that this ideal is not achieved simply by the use of the first person or by the expedient of constructing a text which situates the researcher in the act of research. Instead, Bloom (1997: 112) and Harding (1986: 157-158) confirm that it is achieved by placing the researcher on the same critical plane of analysis as the researched. In other words, researchers are urged to be aware of and disclose their own perspectives, preconceptions, values, interests, and assumptions with which they enter the research process. The researcher's particular assembly of such qualities is not inherently wrong. What is wrong is the failure to critically reflect upon their nature and influence within the research context. Indeed, as Harding (in Bloom 1997: 112) points out, the researcher should never appear as "an invisible, anonymous voice of authority, but as a real, historical individual with concrete, specific desires and interests". The researcher and his or her personal contribution should, in other words, occupy a central, explicit and identifiable position in any report or description of the research process and its findings.

Thus, since I am undeniably part of the social world I study – and importantly, of the social theory I construct – I am urged to remain critically reflective of and render open to scrutiny the ways in which my Self and my subjectivity enter and influence the research process. This practice is likely to decrease any expectation that I am or can be a neutral or "objective" observer. More importantly, it should simultaneously increase my awareness of how the construction of social reality is produced through the specific dynamics of the research context.

The research relationship

The practice of critical reflection is marked by "a concern for recognizing that constructing is a social process, rooted in language, not located inside one's head" (Heaphy 1998: 26). This orientation allows us to see that the researcher's Self is a social Self that interacts with the researched in order to co-construct a product - a social theory - through their engagement. Hence, to free our knowledge, researchers are encouraged to reflect critically upon the nature and implications of the research relationship.

The merit of attempting to subject the nature of the research relationship to close scrutiny is substantiated by Reinharz (1983: 180) who contends that the data provided by participants and, hence, also the research results, are likely to be coloured by the position participants assume or are allowed to assume in relation to the researcher. In other words, where participants are perceived and treated as objects "on whom research operations are performed" (Reinharz 1983: 180), the nature and content of the data they provide are likely to be influenced by their objectified state. Conversely, where research participants are encouraged to become more actively involved in the research process, their contribution to the body of research data may very likely be affected by their perception of the research process as a collaborative enterprise. In the light of this, Rosaldo (1993: 169) recommends that researchers should ask of both themselves and their participants such questions as: "What are the complexities of the speaker's identity? What life experiences have shaped it? Does the person speak from a position of relative dominance or relative subordination?" Through seeking answers to questions such as these, it becomes possible to shift away from focusing only on "what was said" to also inquiring into "who was speaking to whom under what circumstances" (Rosaldo 1993: 214).

This shift in attention will support the freeing of our knowledge by critically reflecting on the positionality of both the researcher and the researched, as well as on the implications thereof. It will also encourage a focus on the minutiae of research relationships. This is in line with Herzfeldt's (in Barbour & Huby 1998: 4) suggestion that it is only through a detailed examination of the minutiae of such relationships that we can aspire to move beyond the categories and classifications of the day. He postulates that "sensitivity to immediate context... helps shift the focus away from perspectives that are already, to some extent, determined by the structures they were set up to examine" (Herzfeldt in Barbour & Huby 1998: 4). This approach may be applied to research and to the relationships it engenders and through which it works. In other words, the practice of critical reflection is extended to

include a focus on the apparently "trivial" qualities of the research relationship as a rich source of data on the ways in which we construct an understanding, a truth, in and through this relationship.

Critical reflection upon the relationships that evolve within the research context should therefore attune researchers to the ways in which the nature of these relationships affected the data obtained and, consequently, also shaped the particular construction of social reality advanced. Berg (1984: 228) contends that such a consideration of the nature and implications of the researcher's relationship with participants needs to be included in any report of the research results. Through this practice the researcher will grant access not only to the specific human context in which the research was conducted, but also to an essential piece of the framework necessary to interpret the research results.

Thus, given that my social theory (as a "truth") was cooperatively constructed in and through a dynamic relationship between my Self and the ME sufferers who participated in my study, I am encouraged to subject this relationship to critical reflection. In this way, I will recognise and make available (read: free or lay open) for scrutiny the distinctively human context in which my research was embedded.

Research strategies

The practice of freeing our knowledge furthermore encourages researchers to critically reflect upon the nature and claims of different research strategies (Morgan 1983b: 375). Within the research context, these strategies in effect shape the ground against which specific human experiences can become figural. In this sense, the strategies that the researcher chooses and implements significantly influence the understanding that he or she will (be able to) develop about the Other.

Morgan (1983b: 375) emphasises that any reflection on the research strategies employed within a particular study should take place in a way that will facilitate exploration rather than constraint. In other words it should encourage researchers to gain a measure of detachment from their usual presuppositions through reflection on the nature and implications of what they and others do in their research. This means that the researcher should not simply assume that a practice favoured in many a textbook can be applied uncritically. Rather, the researcher should ask (and explore possible responses to) questions such as: What will the influence of

this course of action be on the research participant? Will it allow further openness or will it provoke reticence? How will it impact on the balance of power in this relationship? Will it allow me to probe deeper or only cause unnecessary hurt? Will I be able to deal with the possible outcomes of this course of action? Will this be ethically permissible? And under what circumstances will it become unethical? How does this course of action support my own interests? And how will it shape the story I will be able to tell?

Raising pertinent questions such as these will serve to emphasise the infinite importance of critical reflection upon the nature and potential consequences of research strategies. Morgan (1983b: 374-375) contends that such reflection should enable the researcher to view different research strategies as offering different interpretations of a situation or different arguments in favour of understanding a phenomenon in a particular way. This again confirms that claims which construct social reality in a particular way should be treated *as claims*, rather than as statements that purport to be absolute or foundational in some way. By bearing this in mind researchers will become able to render their strategies – and their claims – tentative and open to critical discussion.

Thus, to free my knowledge, it is recommended that I extend the practice of critical reflection to include a consideration of the nature and implications of the research strategies I employ. Such a consideration should sensitise me to the taken-for-granted legitimacy of different research strategies as well as to the potential implications of such strategies for the construction of social reality I produce.

Conclusion

In seeking to evaluate the "truth" of the understanding we as researchers construct of an Other's experience, I submit that we must intentionally strive to free our knowledge. However, such "freeing" is no longer to be pursued through inevitably futile efforts to eliminate the human quality that permeates the social research process. On the contrary, "freeing" is now explicitly directed towards this human quality by striving to lay bare the centrality of the researcher and his or her contribution in all research processes.

I furthermore submit that such a freeing of our knowledge can be executed in concrete terms through the practice of critical reflection. The latter demands a rigorous investigation into the

nature and implications of my own contribution, of my relationship with the research participants, and of the research strategies I employ. Adopting this approach should ideally become a way of "unconcealing" my own tacit world, including the constraints I might have imposed on myself. The insight gained in the process should be included as an integral part of any account of the research that has been conducted. I should, in other words, appear *in person* not only within the research itself, but also within the presentation thereof. In the process of doing so I will lay open to scrutiny the foundation – the very acts of understanding – that support the specific construction of the social reality I am able to develop. I will, in short, free my knowledge.

Freeing my knowledge through such a practice of critical reflection will ideally make it possible to carry out what Douglas (1970: 30) calls the crucial test of "partial reproducibility". The success of such a test within the context of this study would rest on the ability of an outsider to (re-)construct a more or less similar understanding as the one I advance based on the properties of the research process that I lay open to scrutiny. Where I then present a rigorous explication of my way of knowing, I in effect translate my understanding into reproducible terms. Yet, it should be noted that such a translation can never be complete or absolute. Freeing, in the context of social research, will always remain relative.

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Summary

When we, as social researchers, attempt to do justice to a social reality we study, we offer a particular way of understanding that reality; we develop and present a theory or a "truth". Given my status as an ME sufferer, I had to contemplate my own potential impact on the specific truth (or truths) I would develop and present about the realities of suffering caused by ME. Would it be imbued with my own personal interests and preconceptions, or would it present an authentic – truthful – picture of the illness experience of ME sufferers? Could it ever be both? And how would I evaluate it? Finding answers to these questions demanded – as a prerequisite – a better understanding of what we mean by "truth" – and specifically, how it is developed, and how it can be evaluated.

One way of understanding the development of truth in science is by reference to the mirror metaphor. According to this view I have to suspend all subjective involvement within the research context because such involvement would inevitably prejudice, if not entirely invalidate, the image in the mirror, namely my research findings. This approach rests upon a specific concept of objectivity – and specifically upon the assumption that objectivity is positioned in absolute opposition to subjectivity. However, this perceived opposition is based upon a basic misconception within the framework of the mirror metaphor, namely that objectivity and subjectivity are regarded as properties of the researcher. Yet, while subjectivity is indeed a quality of the researcher, objectivity is not. Instead, objectivity is a feature of the research process. "Objective research" implies the use of objective research methods geared towards the achievement of valid research results and not necessarily geared towards the exclusion of all subjective involvement on the part of the researcher. In the light of this insight, the significance of the mirror metaphor on my understanding of the development of truth – and the researcher's subjective involvement in this – declined dramatically.

However, renouncing the mirror metaphor – and specifically the failures of "objectivity" – did not leave me stranded because there is an alternative means of understanding the development of truth within social research, namely social construction. According to this concept, truth as an understanding is something that is co-constructed within an intricate relationship between the person who knows – the knower – and the-to-be-known. The knower brings a substantial part of the Self – his or her subjectivity – to this relationship. The construction of the truths

that I, the researcher, advance can therefore no longer be separated from my own subjective experience of the occurrences which constitute my experiences within the process of research. This view clearly implies a recognition of the researcher's central involvement within the very act of knowing.

The fact that the "I" of the researcher is ever present and involved in the development – or rather construction – of social theory holds critical implications for the evaluation of the truth-value of the social theory developed through social research. I submit that the most practical and productive means of evaluating the truth-value of such a theory is by freeing our knowledge – not by eliminating the researcher's contribution in the name of "objectivity" – but by rendering it entirely open to the scrutiny of others. We can achieve this through the practice of critical reflection, which is the researcher's responsibility to render an explicit account of the Self in the process of theory development. I will show in Part V that without such an account the truth-value of a theory, of any understanding, is likely to remain concealed behind unexposed areas of fusion between the researcher and the researched.

PART III

Introduction

Research begins with a question.

My research question in this study was directed at the development of a greater understanding of the illness experiences of those who suffer from ME. At the same time, my personal history called for a strong methodological concern with my own experiences within and contributions to the research process and its final product. Taken together, the guiding research focus of the present study therefore demanded a deliberate and all-embracing interest in the world of human experience.

In accordance with Pollio et al's. (1997: 28) view, this primary concern with a realm of human experience introduces "a situation appropriate to the original meaning of the word method, *a meaning that combines the word* hodos, *a path or way, with the word* meta, *across or beyond. Under this rendering, method is not an algorithmic procedure to be followed mechanically if useful results are to be achieved, rather, method is a way or path toward understanding that is as sensitive to its phenomenon as to its own orderly and self-correcting aspects". The present study, then, required a method not only appropriate to the investigation of the human world I had sought to understand, but also highly sensitive in its application within this world.*

With this in mind, I set out to select the most appropriate and sensitive methodological approach through which to steer this study towards a progressive understanding of human experience. This methodological approach is described in Part III.

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Chapter 8

First steps: Setting the stage for data collection

In preparation for the process of investigation and analysis it was necessary to achieve two objectives. The first was to define the stance that would guide my methodological approach throughout this study. My choice in this respect would directly influence the extent to which I would be able to apply the epistemological perspective adopted in Part II. Secondly, I had to familiarise myself with the specific field of study. I considered this of great importance in making me sufficiently sensitive to the pertinent issues that permeate the field. The steps I took to achieve these objectives are described in Chapter 8.

My stance; my choice of method

Through the work of Douglas (1970: 13) I was able to recognise that my choice of method for investigation and analysis would be significantly influenced by the stance I chose to adopt toward the social (human) reality I wished to study. That is, my stance toward the social world in question would determine the method I chose – not the method my stance.

My decision to let my stance determine my choice of method is the exact opposite of the classical scientific approach to investigating the social world. The classical approach is to assume that there is only one general set of criteria for scientific "truth", and that it is embedded in the classical works of the natural sciences. Thus, the early social scientists adopted a conscious policy of studying the social world in the same way one would study any physical object. Having so presupposed these methods, they adopted the stance most in accord with them. They adopted what Douglas (1970: 14) calls the *objectivist stance* toward the social world. Accordingly, the early social scientists assumed, as Douglas (1970: 13-14) goes on to explain, that the phenomena of the social world could and should be studied only in terms of clear, distinct and formal ("scientific") categories that they would define in advance of their studies. They even assumed that decisions about how one would determine whether the results of a study were "true" or "false" could and should be made in advance of the study. In a very significant (and very disconcerting) sense, these assumptions as the classical ideals of the early social scientists still closely correspond with many of the "methodological ideals" often espoused in modern day social research textbooks.

However, in choosing a stance to guide my methodological design, there was an alternative to the objectivist perspective . In fact, there was an entirely opposite extreme which Douglas (1970: 14) labels the *natural stance*. This is a stance "in which the everyday world is taken for granted as it is experienced in everyday life. It is that stance taken by the individual within the stream of everyday life. It is a stance that does not raise serious and persistent questions concerning the nature of the everyday experience but, instead, takes that experience as a fact". The natural stance, then, is supposed to be the one taken by the individual in everyday human life, though whether or not individuals in fact do take this stance is certainly a matter open to debate. However, I could not adopt the natural stance because in my research I do ask questions, I do long for understanding, and I do not simply accept everything as "fact". Thus, like the objectivist stance, the natural stance did not present to me a desirable choice of stance through which to direct my investigation.

Douglas (1970: 25) identifies still a further alternative, namely the *theoretic stance* which occupies the middle ground between extremes. To take this stance toward the social reality that is being studied means, for Douglas, "to stand back from, reflect upon, to re-view the experience taken for granted in the natural stance. To take the theoretic stance is to treat the everyday world as a phenomenon". At its most basic level, this stance involves what Husserl (in Douglas 1970: 25) called "phenomenological suspension" or "reduction". According to the latter the researcher places that which is taken for granted into "phenomenological doubt", thereby making explicit to consciousness the general thesis which unconsciously underlies every individual judgement made within ordinary life, about ordinary life. However, there is a problem with this approach because complete "suspension", as Pollio et al. (1997: 47) point out, is simply impossible to achieve. Thus, adherence to the theoretic stance would place unnecessarily onerous demands on the researcher. I would simply not measure up. What is more, I did not want to measure up because to suspend my very way of knowing would deny my presence within the study – and I most certainly was present.

Thus, I did not choose the extreme objectivist stance for I did not wish my method to artificially determine the stance. Nor did I choose the extreme natural stance for I could not blindly accept everything perceived a matter of fact. And I did not opt for the middle-road theoretic stance, because suspending my way of being and knowing did not present an acceptable or even feasible option to me.

In finally defining my guiding stance I chose to agree with Pollio et al. (1997: 28) that, in seeking to understand human experience, it is necessary to recognise the "perspectival nature of human experience". Participants' world of experience would not be given to me in any direct fashion. I could not share the exact point of view from which they bestowed (and was still bestowing) meaning onto their lived experiences. We were looking at these experiences from different points of view; our perspectives differed. Consequently, what they would describe would reflect their own perspective. Similarly, what I would see would not only be partial, but also very much tainted by my own peculiar perspective. In each case, the description of human experience would bear the mark of the knowing mind at work. Thus, in choosing a stance from which to launch this study of human experience, I had the option of acknowledging the influence of personal perspective and so to remain sensitive to the influence of the knower on both the research process and the product thereof. In short, I had the option of adopting the *perspectival stance*, and this I did.

The process

Like Maso (1995: 17-18) I believe that to be able to appreciate the descriptions of human experience presented in the following two chapters, it is necessary to recapitulate what had been done in order to construct them. I will now, therefore, briefly outline the research process that I followed, and discuss its constituent elements in more detail in subsequent sections.

The research process most closely resembled the (multiple) case study design as described by Yin (1984: 14-52). I selected this distinctly qualitative research design as the guiding methodological beacon because, as Yin explains, it is explicitly geared towards the attainment of a comprehensive understanding of particularly complex social phenomena. Moreover, the case study design acknowledges the importance of context and perspective in the development of such an in-depth understanding. To this end, it also allows for the use of multiple sources of data. In this way the case study design carried the promise of being both appropriate for and sensitive to the concept of an intimate description of human experience.

I followed the advice of Rubin and Rubin (1995: 43-48) by seeking to both support and enhance the case study design through a firm emphasis on the flexible, continuous and iterative nature of the research process as a whole. I had therefore deliberately set out to conduct a study flexible enough not only to explore unanticipated areas of interest, but also to

accommodate the participants in terms of what they knew best. The continuous nature of the research process similarly allowed me to rethink and adjust the research design so as to pursue emerging themes. In addition, it helped me to remain steadily on course toward reaching a satisfying conclusion to the study. To ensure that such a conclusion would be thoroughly founded upon the descriptions and understandings of the participants themselves, the iterative process of gathering data, subjecting it to preliminarily analysis and finally filtering it characterised the entire course of the study. I was thus able to pursue both the foreseeable and the unforeseen not only in an organised manner and in a way that was sensitive to the world of human experience, but was also unwavering in its commitment to develop a comprehensive understanding of the reality being studied.

One can develop better insight into the remarkably dynamic research process employed in this study by looking at its constitutive elements or phases as shown schematically in Figure 4.1. They will be discussed in more detail in subsequent sections.

The diagram in Figure 4.1 highlights the fact that, perhaps more than in any other type of research, the "phases of work in qualitative research overlap and are intermeshed" (Weiss 1994: 14). Why then present the "phases" of the research process as a logical sequence in Figure 4.1 if in practice they are so fused and intertwined? Perhaps ultimately the most important reason is that my account of the research process has been constrained by the use of text as the only medium through which I could present it. Text imposes a linear and sequential mode of explanation that is not always appropriate to what is being explained (cf. Dey 1993: 38), but nevertheless permits a good insight into what was accomplished. Thus, although Figure 4.1 does help to create a multi-dimensional space in which to present the multiple facets of my research, I still depend on text (such as in the subsequent sections) to add the necessary depth, density and clarity to what I wish to say.

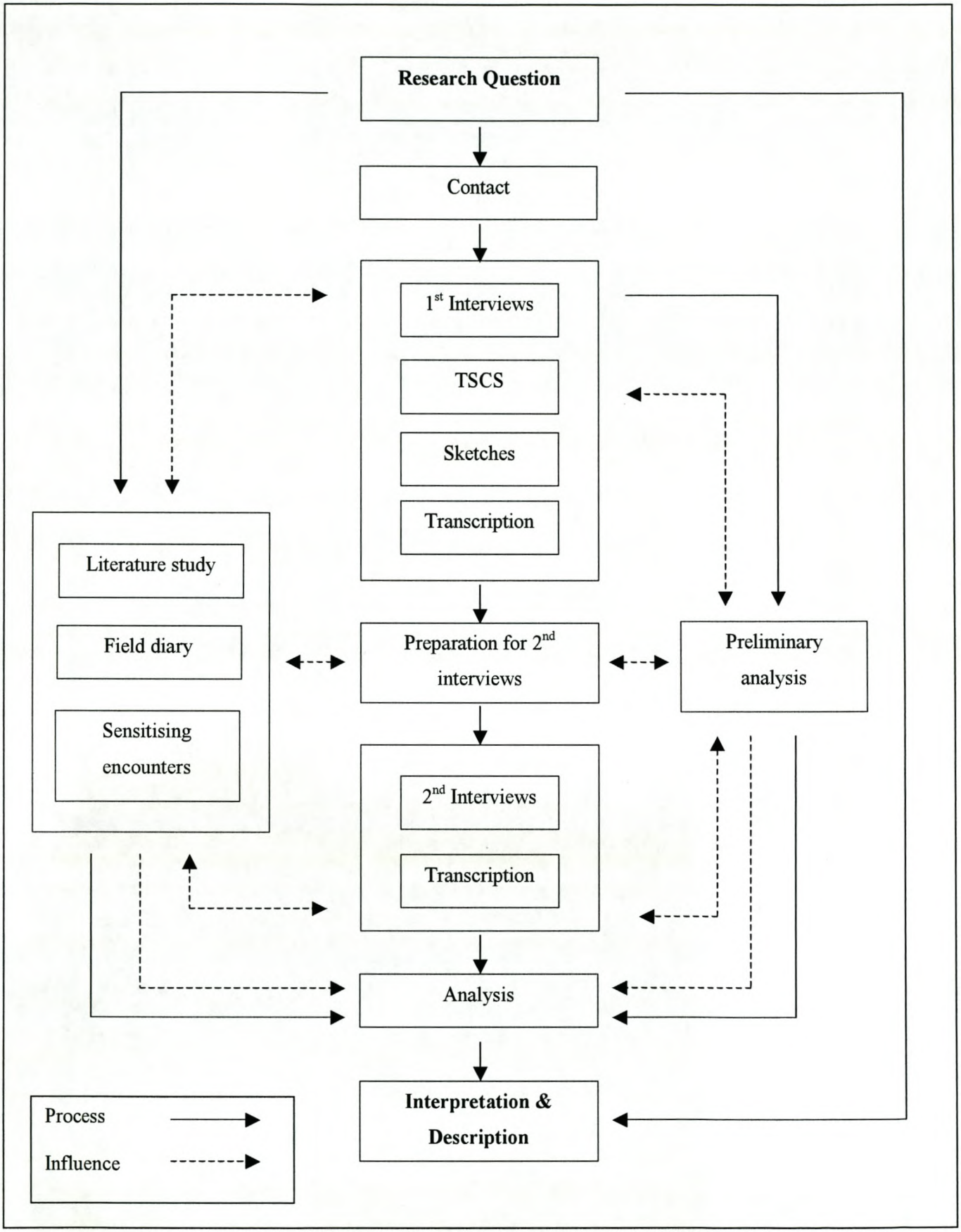

Figure 4.1 A schematic representation of the research process

Initiating steps; continuous conduct

At the start of this study I took three steps concurrently: I became familiar with the relevant literature, I became notably more aware of my own experiences, and I became involved in sensitising encounters with specific others. Although at first thought of as merely representing the inaugural stage of the research endeavour, these maiden steps soon proved to be of a continuous nature, indeed lasting throughout the course of the research process.

Literature

As so many researchers before me (Lee 1993: 73; Snow et al. 1986: 401, Strauss & Corbin 1990: 42), I regarded the use of literature of great importance in this study.

In following the example set by Strauss and Corbin (1990: 48) I was able to distinguish between two types of literature. The first, academic or technical literature, included reports of pertinent research studies as well as theoretical and philosophical papers characteristic of professional and disciplinary writing. The second was popular or non-technical literature which included a wide variety of documents such as articles in popular magazines and newspapers, newsletters from the South African ME support organisation (MESA), and the communications of relevant newsgroups on the Internet.

Each of these sources of information was purposefully mined for the data they contained. Throughout the research process the often extensive, and at times even surprising, information gathered in the process was directed at complementing not only other sources of data but also different procedures and findings. Moreover, through providing a rich background of information, a thorough acquaintance with the relevant literature also served to enhance my ability to develop insight into and understanding of the human world being studied. As Strauss and Corbin (1990: 42) predicted, it "sensitised" me to the chosen field of research.

As a final word on the use of literature I must add that although I was very much aware of the importance of incorporating and using different types of literature throughout the course of the study, I also consciously tried to "guard against becoming captive of any of them" (Strauss & Corbin 1990: 56). In other words, while all literature I consulted certainly contributed to the development of a greater understanding of the subject, I did not wish this understanding to be co-opted by and made into a devoted disciple of any one of them.

Field diary

Edwards (1993: 184-185) says that, far from being a simple recording instrument through which participants are able to voice their personal experiences, the researcher is a central part of – or as Dey (1993: 37) asserts, a participant in – the research process. While this recognition is pertinent to all social research, it is even more so in this study, given the focus of its inquiry.

As an inevitable participant in the research process the researcher is, as Adler and Adler (1987: 84-86) show, very often compelled to draw upon the complex and multifaceted experience of his or her human Self. Such an employment of personal experience assists the researcher in achieving the most intimate understanding of the social world being studied. Perhaps one reason why this is so true is that the research process is such an interactive one (cf. Edwards 1993: 185-195). In other words, the understanding that the researcher eventually reaches in the course of the study depends not only on what participants had actually experienced, but also largely on how they constructed these experiences in and through their relationship with the researcher. The researcher needs to be aware of his or her Selfand its contribution to the research relationship in order to be as open and responsive as possible to participants and their constructions (Dey 1993: 239-240). In this way, the researcher can attend in a personal, disciplined, and sensitive manner to what is being constructed. In fact, when the researcher's own thoughts and feelings no longer loom unexamined, they become an important source of insight, which leads to a better understanding of the human world of the participants.

Since the researcher's own contribution is of such profound significance it constitutes a very legitimate and pertinent object of analysis. In fact, as many authors (Devault 1990: 104; Dey 1993: 37; Edwards 1993: 184; Lee 1993: 105) assert, the researcher's own actions, interpretations and experiences must be analysed as an integral part of the research process itself. Such analysis would then serve to render the researcher's own contribution open to scrutiny by others.

A vital source of such an analysis of the researcher's own contribution is, as Dey (1993: 37, 239-240) points out, is the researcher's own field diary. With this in mind, I set out from the beginning of this study to document my own contribution in a field diary. In this diary I attempted to disclose my Self – my very being – as a significant source of both insight and knowing. I explained the reasoning behind procedures I had employed and reflected upon the multitude of encounters I had experienced. I noted and examined my social characteristics as

well as my assumptions, beliefs, and presuppositions in terms of their effects upon the research itself as well as upon the final understanding which was to be constructed. In fact, I detailed my very personal experience of every instant of the research endeavour. In the process I was able to trace my journey through the entire research process, from the very first steps where I identified an appropriate conceptual focus for the study, right through to the final efforts to produce an integrated account.

As a result, my field diary produced a wealth of material on which I was able to draw throughout the research and in particular during a more detailed explanation of my own research experience (as presented in Part V). Indeed, through my field diary, I could consciously draw upon my own experiences and use it to offer new ways of looking at the reality of others. What is more, I could do so in a manner that was not only sensitive and disciplined, but also explicitly open to the scrutiny of those who cared to make the effort.

Sensitising encounters

Throughout the research process I have been involved in conversations with people, both locally and abroad, who have knowledge of and/or experience within the research field in question (cf. Lee 1993: 73). These have included communications with medical practitioners who care for ME sufferers, with leaders who champion ME and ME-related support organisations, with relatives of sufferers, with sufferers who have "recovered", and with sufferers who are still ill but who fell outside the selection criteria for this study. Each of these encounters served not only to shape and sharpen my awareness, but also to mould the understanding of the illness experiences of ME sufferers that I was eventually able to construct.

Thus, throughout the course of this study, I have studied the relevant literature, documented my own contribution, and learned from those in the know. All in all, I had sought to be as sensitive to and informed of the governing area of interest as I could possibly be. For me, this area of interest did, after all, represent an area of uncertainty which I longed to expunge.

Conclusion

I had undertaken a number of preliminary steps to set the stage for a study which was geared to develop a comprehensive description of human experience as it is lived and described by selected individuals. These steps not only informed and sensitised me to the particular field of study, but also clearly agreed with the epistemological approach which I adopted in Part II.

The perspectival approach that I adopted as a guiding stance in this study echoes the essential elements of the metaphor of construction. It acknowledges that "truth" – my description of the field of study – is produced within a relationship in which those aspects that do become figural will be directly influenced by the perspective adopted by the knower.

As I showed in Part II, such a recognition of the knower's contribution to the research process demands an explanation of the nature of this contribution – not only to stimulate a greater awareness of and sensitivity to it, but also to render it accessible to the scrutiny of others. To achieve this end the field diary was very deliberately employed in this study. This instrument has allowed me to explore my contribution throughout the research process – and, importantly, to explain its essence in Part V.

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Chapter 9

Getting through the door – and to the data

Chapter 9 outlines the process I followed to enter the human world of ME. Once "inside", it became possible to work with the research participants in developing (or constructing) a better understanding of the subjective illness experience of ME sufferers. In depicting the ways in which I set out to do this, Chapter 9 will resonate key elements of the epistemological approach adopted in Part II. This means that it will be possible to identify traces of concepts such as relationship, context and perspective throughout the text.

Contact: Getting in touch

At the outset of the study it was envisaged that a limited number of ME sufferers would be selected for participation.

Selection criteria

ME sufferers had to comply with a number of specified criteria to qualify for participation in this study.

In order to limit the number of confounding variables, I decided to select participants who would share a similar demographic profile, specifically regarding gender, age, location, and medical status. I therefore sought to select only *female* participants, who fell within the *age group 20-50*, and who were living in the *Western Cape region* at the time of the study. I also selected only those sufferers who had been *medically diagnosed* as suffering from ME. I do recognise, however, that as both the 1988 and 1994 case definitions of ME used in the medical profession to diagnose ME are beset by severe problems (cf. Chapter 2 as well as Jason et al. 1997), this dire state of affairs might have introduced a certain degree of bias into the present study, either by possibly excluding legitimate cases or including illegitimate cases.

In addition, in following the recommendation of Rubin and Rubin (1995: 66), I selected participants who were particularly *knowledgeable* about the proposed research question. This criterion correspond with what Spradley (1979: 47-49) describes as participants who are both

thoroughly encultured and currently involved. Participants therefore had to be fully acquainted with the experience of ME and had to use this knowledge to guide their actions on a regular basis. Furthermore, participants had to be willing to *openly participate* in the proposed research enterprise and so fully share their experience of ME. According to Rubin and Rubin's (1995: 66-67) discussion, adherence to this criterion would assist me directly in avoiding idealised or fictionalised answers. Lastly, research participants had to be able to grant *sufficient time* (and energy) to engage in the proposed study (Spradley 1979: 51-52).

Eventually, four ME sufferers who met all of the above stated criteria were selected to participate in the study. Although I hesitate to declare that this group of participants is wholly representative of all the different aspects concerning the particular research question, I do believe that this particular selection of participants allowed me to develop a well-balanced and in-depth understanding of the ME illness experience (cf. Rubin & Rubin 1995: 69-70).

Recruitment strategies

Like Lee and Renzetti (1993: 30) I soon realised that the problems deriving from the recruitment of research participants in a study about a sensitive topic among a sensitive population were particularly acute. To clarify this statement I will describe how I located and selected the participants for this study.

In following the example of Martin and Dean (1993: 86), I had adopted a combination of recruitment strategies. The rationale behind this approach was that recruitment from a variety of sources would help to ensure diversity in the selection of participants. In the process, I had employed the help of the medical profession, made use of lists, placed advertisements, used personal referral and, to a limited extent, attempted my hand at network sampling.

In every case, when a potential participant was located, the initial contact was promptly followed up by a friendly letter which introduced me as the researcher, set out a preliminary outline of the proposed study, and contained a statement conveying the official endorsement of the proposed study from the University (cf. Appendix A).

Physician referral

Jason et al. (1997: 976) recommend the medical profession as an important source for finding ME sufferers. Since medical records are confidential, a physician closely involved in the

present study offered to contact ME patients on my behalf and to explain the nature of the proposed study to them. This line of recruitment produced one participant.

Heeding the advice of Jason et al. (1997: 981) I was wary of relying solely on physician referral. I recognised that if I did so, I could introduce a significant degree of bias into the selection of participants through an emphasis on help-seeking behaviour as well as through assuming access to the health care system.

The use of lists

I had contacted the ME Association of South Africa (MESA) in the hope of obtaining a list of their members or at least of their newsletter's subscription list. I was aware that such a list would inevitably be incomplete and could therefore introduce a measure of bias into the study. Still, I reasoned that should the list contain a large percentage of the specific population of ME sufferers, the cost of locating ME sufferers who are not on the list would by far outweigh the possible bias in using the list (cf. Sudman & Kalton 1986: 403).

However, almost predictably, MESA considered their membership list too confidential to share. I therefore had to follow a different route.

Advertising

To secure access to the readership of the MESA newsletter I placed a carefully worded letter in the April/May 1999 edition of the quarterly MESA newsletter. I explained the essence of the proposed study, emphasised its importance, and set out its selection criteria. Throughout I attempted to convey my sincere respect for ME sufferers and their illness experience. In doing so, I wished not only to broaden the coverage enjoyed by the research, but also to present it in a positive and non-threatening manner so as to encourage ME sufferers to come forward and contact me (cf. Biernacki & Waldorf 1981: 149; Lee 1993: 71-72).

The letter placed in the April/May 1999 edition of the quarterly MESA newsletter elicited a total of five responses which eventually led to the selection of two participants.

Personal referral

In every encounter with an ME sufferer or anyone knowledgeable in this regard, I attempted to foster additional contacts within the ME community. I deliberately (and frequently) inquired whether they knew of any acquaintances who might be interested in the proposed study. The process of personal referral was clearly a matter of "a friend of a friend of a friend knowing someone... who perhaps, just perhaps might be interested". In this process, where I had relied so strongly on those "intermediaries" spreading the word, it was inevitable that chance would play an indispensable role (cf. Biernacki & Waldorf 1981: 150-155).

Still, despite its somewhat haphazard nature, this approach produced a number of significant contacts and ultimately led to the selection of one participant.

Network sampling

Initially I had reasoned that each of the recruitment strategies discussed above would, even if it did not yield suitable participants in itself, at the very least sow the seeds for further network sampling (cf. Lee 1993: 63). This recruitment strategy, also known as snowball sampling, is an approach that "yields a study sample through referrals made among people who have or know others who possess some characteristics that are of research interest" (Biernacki & Waldorf 1981: 141). It is regarded as a strategy particularly well-suited for the recruitment of rare or sensitive populations and relies very heavily on the assumption that members of such populations often know each other (Biernacki & Waldorf 1981: 141; Lee 1993: 65-67; Sudman & Kalton 1986: 413).

For the purpose of effective network sampling, Biernacki and Waldorf (1981: 146) recommend that the researcher should start referral chains among members of the special population using relevant available knowledge concerning the specific population and its members' possible location. I tried this with little or no result. Biernacki and Waldorf (1981: 147) also points out that such chains of referral tend to develop and diverge as the researcher becomes more sensitive and attentive to the particular field of research. However, even when I became deeply steeped in the research area neither spontaneous nor deliberately elicited contacts were forthcoming. In fact, almost every effort to initiate or develop referral chains failed. Despite its name, snowball sampling did not evoke a growing mass of contacts. In fact, it did not yield a single participant for this study.

Thus my efforts to locate and recruit potentially suitable participants for this study were often frustrated. The tremendous difficulty I encountered in this process is very likely related to the fact that the ME community constitute, as Biernacki and Waldorf's (1981: 144) describe it, a "target population" with "low social visibility". In other words this community is surrounded by and enmeshed within the moral, legal, social and medical dilemmas and sensitivities evoked by the illness that distinguishes it. This state of affairs has rendered this community stigmatised and isolated – and quite possibly wary of yet another (derogatory) study which would prove to be nothing but a waste of time and energy.

What is more, the members of the Western Cape ME community clearly do not necessarily know or are aware of one another. This might have something to do with the fact that support groups within this region were only operative for a short time during the late 1980's and early 1990's and were even then scattered over a large area. ME sufferers in the area therefore did not have any organised opportunity to meet with other sufferers. Hence, my struggle to make use of any type of referral.

Biernacki and Waldorf (1981: 144-145) explain that the ideal method for locating people who maintain such low visibility and who share very little contact would be to draw a representative sample of, say, all adults in the Western Cape population. Then, assuming the honesty of respondents, the researcher would screen the sample to locate those cases identified as members of the specific target population. However, the considerable costs involved in drawing a large enough sample in order to locate a sufficient number of such members ruled out this approach. In addition, the aim of a particular study that focuses on such a sensitive population may not necessarily be to test a series of predetermined hypotheses on a representative sample which would allow for extrapolation to the whole population. On the contrary, such studies are very often more explicitly directed at developing an in-depth understanding (not a compilation of statistical findings!) of the particular human experience in question. For this, such studies do not need a representative sample based upon the principles of probability. Here, as in my study, the aim is not generalisation; it is understanding and insight.

To summarise: in order to develop an intimate understanding of the illness experience of ME I used a combination of recruitment strategies to select four ME sufferers who complied with the selection criteria. This process encountered various degrees of difficulty and testified to the

critical necessity of taking the greatest care when dealing with such a highly sensitive population.

The in-depth interview

Like Oakley (1981: 32) I believe that an interview is essentially a way of finding out about people. Asking questions is indeed the main source of social scientific understanding of human experience, of human life. Thus the interview, then, represents an important instrument of data collection in general and particularly for this study.

The rationale: Why in-depth interviewing?

Authors such as Lee (1993: 104) as well as Rubin and Rubin (1995: 51-52) are convinced that the in-depth or qualitative research interview represents an exceptionally sensitive and well-suited means of developing an intimate understanding of experiences best communicated through rich narratives and detailed examples (Lee 1993: 104; Rubin & Rubin 1995: 51-52). Thus, based on its established reputation, the in-depth interview stands virtually alone as an instrument through which to develop thorough descriptions of human experience that might be difficult to attain otherwise.

Closer inspection of this instrument reveals that it has hidden strengths. Indeed, when I turn to Kvale's (1996: 36-37) discussion of qualitative interviewing, it becomes clear that the in-depth interview actually has three dimensions. For Kvale the research interview is, firstly, "a specific professional form of conversational technique in which knowledge is constructed through the interaction of interviewer and interviewee". Secondly, the research interview is "a basic mode of knowing' in accordance with which the certainty of our knowing becomes 'a matter of conversation between persons, rather than a matter of interaction with a non-human reality". Thirdly, the research interview is "constitutive" of those involved as well as of their world. In this sense, the human world of experience becomes a 'conversational reality'. Thus, the research interview represents much more than an empirical method of study. It also represents a basic mode of constituting knowledge through an interactive process of conversation.

Throughout Kvale's consideration of the research interview he strongly stresses its essentially "inter-active" nature. Accordingly, the researcher is no longer simply concerned with passively collecting the participant's statements like gathering pebbles on the beach. No, the researcher is much more directly involved as he or she actively steers and co-determines the entire course and nature of the interview (Kvale 1996: 183). Consequently, the knowledge that is constructed in the interview cannot be accepted as an independent given, let alone as a direct representation of an underlying ("really real") reality. Rather, the knowledge that is constituted through the research interview is a socially co-constructed creation. It is, in Kvale's (1996: 124-125) words, "created inter the points of view of the interviewer and the interviewee". In this sense, the research interview is a specific form of human interaction through which knowledge is produced interactively.

An understanding of the interactive, interrelational construction of knowledge within the interview compels a consideration of the power relationship between the researcher and the researched. Here it becomes important to recognise as Kvale (1996: 227) does that, whatever may be attempted, the research interview "is not a reciprocal interaction of two equal partners. There is a definite asymmetry of power".

The asymmetry of power within the research interview stems, as Brannen (1988: 554-557) shows, from two primary sources: the control over interaction and the control of information.

The first source of power concerns the ability of the researcher to control the interaction itself by commanding both the form and the content of the interview. Within the in-depth research interview, where the format is not rigidly specified, the locus of control at any one moment will emerge interrelationally. The participants thus have the opportunity to control the interview and, hence, to dictate its form and content. Where this is allowed to happen, the exercise of power in the interview has the potential of more genuinely becoming a two-way process – with power being exerted by both researcher and researched.

The second source of power lies in one participant having power over the other participant by virtue of possessing sensitive or even damaging information. The researcher usually not only possesses such information, but also has the power to interpret it; that is, to attribute meaning to the descriptions of participants. For Kvale (1996: 227-228) the danger here is one of 'expertification" where the "expert" researcher expropriates meaning from participants' descriptions and reifies it into 'the real meaning' of their experiences so as to give expression

to some "more basic" reality. In the process, participants may be rendered vulnerable individually and collectively as they have very little control over how the researcher or anyone else interprets their stories (cf. Finch 1984: 85). Within the in-depth interview, as seen by Kvale, there is no question about some "more basic reality". The stories told by participants within the dynamic (power-laden) research relationship is a product of and, therefore, directly contingent on this very relationship (cf. Cunningham-Burley 1985: 76). It is not a given. It is not to be worked through or attributed extra "expert" meaning. For there is no more "really real" reality, no more "basic" knowledge, than that constituted by and through participants' descriptions.

Because of its well-established reputation as well as the more powerful conceptualisation of its nature, the in-depth research interview appeared the most appropriate – and the most promising – option for me to follow. It indeed contained the ability both to capture the richness and complexity inherent in the illness experience of participants and to accentuate and illuminate the researcher's own experience of and within the research process. Thus, the in-depth interview could not be excluded from the design of a sensitive methodological approach for this study.

The interview design: How did it work?

Direction

In order to facilitate the development of an intimate understanding of human experience within this study, I adhered to the advice of Rubin and Rubin (1995: 76-81) in explicitly directing the entire interview design towards depth, detail, vividness and nuance. Depth is an attempt to elicit thoughtful accounts from different participants in order to gain access to different points of view and to different meanings and ways of understanding. Detail adds substance, thickness and clarity to the accounts provided by participants. Vividness is supplied by the stimulating first hand descriptions given by participants, while nuance facilitates an exploration of the subtlety of meaning.

In combination, these qualities served not only to enhance the richness of the data collected, but also to enable me to present strongly convincing support for my final description. In addition, I believe that a deliberate focus on such pertinent qualities of design enhanced the communicability and, thereby, also the credibility of the study as a whole.

Interview guide

The "semi-structured" (Kvale 1996: 124) nature of the interview approach adopted in this study required the design of an interview guide. Weiss (1994: 48) defines an interview guide as "a listing of areas to be covered in the interview along with, for each area, a listing of topics or questions that together will suggest lines of inquiry". The interview guide therefore serves as a basis for the interview, an "orienting framework" (Laslett & Rapoport 1975: 970) for the systematic exploration of the particular field of research.

In constructing an interview guide for both the first (Appendix B) and the second (Appendix C) round of interviews I heeded the advice of Weiss (1994: 48) by listing the lines of inquiry so that they could be grasped at a glance, with just enough detail to make clear what information was desired. Although I did foresee possible questions, I did not include these into the final interview guide as I wished to ordain each interview guide with a substantial measure of openness to change.

An openness to change rightfully suggests that I did not plan to apply the designed interview guides rigidly. Indeed, instead of strictly following every area of interest as listed, it was more important for me to permit the participants to talk about what they wanted to talk about in a way most meaningful to them, provided that it was at least somewhere near the focus of the study. Like Weiss (1994: 48-49), I sincerely believed that allowing the participants to do so would invariably produce better data than plodding faithfully along lines set out in the interview guide. After all, the ultimate goal of every interview (and indeed of the entire research process) was for the participants to develop a construction of their own experience in their own way (cf. Laslett & Rapoport 1975: 970).

Wording of questions

In considering the wording of those questions employed within the interview situation, I looked to Kvale (1996: 129) for advice. He suggests that every interview question should be evaluated in respect of two crucial dimensions: the dynamic and the thematic.

The dynamic dimension of interview questions aims to promote a warm and amiable research relationship. I thus aimed to make every research question contribute to the establishment of a positive interaction between myself and the participant, to engender a steady flow of conversation, and to motivate the participant to give full expression to her experiences.

The thematic dimension of interview questions aims to show the relevance of the question for the research theme. To do so, it was important that every research question should serve to inspire the participants to base their accounts on actual experiences. I therefore deliberately worded interview questions to clearly suggest the desired level of thoughtfulness and detail required in the response. In other words, I asked participants to particularise. For instance, "Could you walk me through the last time you visited a doctor, just what happened?" Or, "Is there a specific instance you have in mind when you say...?" Also, "Could you tell me what happened there, starting from the very beginning?" In asking for and about specifics, I attempted to avoid accounts which are framed within what Weiss (1994: 72) calls the "generalized present". This is a tense participant's "most frequently employ for a generalized description. It summarizes developments that occurred in the past and continue through the present". In effect, when the participants provide generalised accounts, "their description expresses a kind of theory of what is most typical or most nearly essential in the class of the event". By doing this, the participants in a sense pre-empted my interpretation and analysis. Thus the need for particularisation.

A good interview question, then, is required to contribute dynamically in order to promote positive interview interaction, and thematically in order to contribute to sound knowledge production. The decisive issue in this study was not whether my questions could be condemned as leading or not. Rather, as for Kvale (1996: 159), the issue was where my interview questions were leading and whether they were leading in the direction of an in-depth description of human experience as produced through conversation.

Number of interviews

Brannen (1988: 557-559) and others have suggested that when conducting sensitive research it is imperative that interviews should not be repeated. There should be no fear on the part of the participant that his or her path will ever cross again with that of the researcher. When the research relationship exists only for the purpose of the research and is terminated as soon as the interview is completed, the researcher cannot exercise any social control over the participant. It is said that a single encounter with a "friendly stranger" (Cotterill 1992: 596) is likely to permit the participant to talk openly about highly sensitive areas of interest, without the fear of any aftermath. This is a reasonable contention, especially given the argument that the relationship between disclosure and intimacy is a curvilinear one. In other words, as Lee (1993: 113) explains, the recipients of intimate details about a person's life are most likely to

be either those standing in a very intimate relationship to the person, or those who are socially very remote like the "friendly stranger".

On the other hand Laslett and Rapoport's (1975: 973-974) argue that a one-off interview may be insufficient and that the "inter interview dynamic", particularly the period between the first and second interviews, is of crucial importance. What is usually presented during the first interview is a more publicly acceptable "surface" account whereas, typically, a more complete and deeper account is likely to emerge at the subsequent interview. Cotterill (1992: 595) and Ribbens (1989: 580) suggest that the difference in the nature of the accounts constructed during the first and second interviews may be related to the dissimilar levels of familiarity and intimacy experienced by the participant in these two settings. So, during the first interview, the participant may be acutely aware of the need to manage his or her conduct within this extremely unfamiliar situation shared with someone who is regarded as a stranger. Consequently, during many first interviews participants are likely to produce a "public" account as they attempt to accommodate the researcher by making the "right" responses. This does not mean that they are deliberately trying to deceive the researcher, but rather that they are merely abiding by culturally defined rules of appropriate behaviour between strangers in unfamiliar situations. By the time of the second interview a higher level of trust, confidence and familiarity has been established within a more intimate research relationship. From now on more "private" accounts are likely to emerge. These arguments convinced me that it would be desirable to interview all participants more than once. I therefore designed the research process to include two in-depth interviews conducted individually with each of the four participants. Whether more than two interviews would take place with any of the participants would depend on the participants' state of health, the possibility and/or necessity of postponement, and the quality of coverage of those areas pertinent to this study.

The first set of interviews closely corresponded with what Rubin and Rubin (1995: 28) describe as "cultural interviews". That is, they focused on the participant's experience as an integrated entity. Participants were allowed considerable freedom to explore and define their experiences in their own way. I hoped that our first interaction would sensitise participants to the areas of concern in the study and so prepare them for our subsequent encounter. Also, I made a conscious effort during the first interview to establish a good research relationship so that the participants and I could get to know one another better and achieve a sense of the rhythm and flow of our exchange and interaction (cf. Weiss 1994: 57).

The second round of interviews assumed the form of "topical interviews" (Rubin & Rubin 1995: 28-31). Based upon the extensive descriptions obtained during the first interviews, these encounters focused more narrowly ("zoomed in", so to speak) on specific areas of the participants' experiences. The main objective at this stage was to secure and clarify detail, example and context. As in the first interviews, the second encounters were marked by a strong emphasis on the sensitive management of our interaction.

Thus, the desire to establish more familiar and intimate relations with the participants and in this way to develop the fullest possible construction of their experiences, led to my carrying out two interviews with each participant. These interviews had the potential of providing a comprehensive but detailed understanding of human experience.

Length of interviews

Throughout the interview process I followed Weiss (1994: 57) in believing it to be good policy to support the participant in constructing the fullest possible account and, hence, to continue an interview as long as it was productive. Nevertheless, interviewing can be – and was – exceptionally taxing. It did, after all, require unswerving attention, intense sensitivity, and constant monitoring of our interaction, of my own performance, of the material collected, and of practical matters such as the tape recorder. I soon discovered that I could only do it (and do it well) for a limited period of time. I therefore tried not to schedule too many interviews in short succession of each another and certainly not more than one a day.

However, I still found certain interviews extremely exhausting. In such cases, when I became too weary to be fully in touch with what was being constructed, and if it was possible to schedule another interview, I would call a halt. It was then time to take a break, make a pot of tea and talk more casually before returning to the interview itself or arranging that the interview be continued at a different time. However, when a participant lived far from me, say a two- or even four-hour drive out and back, and there was no possibility of rescheduling, I would commit myself to the interview and would stay as long as there was material to cover and descriptions to construct.

The duration of interviews varied greatly. While the shortest lasted a comfortable (and generally acceptable) 1½ hours, the longest interview continued for an exceptional time of 9 hours, the drive there and back excluded! Predictably, one of the most prominent factors

influencing the duration of interviews was the participant's state of health at the time; how much energy did she have to tell her tale, to speak to me, to construct her experiences with me. This seems to correspond very closely with Cannon's (1989: 67) experience while studying the subjective illness experience of those suffering from breast cancer. For her, as for me, participants' health represented a deciding factor in determining the length of time an interview could be endured.

Location of interviews

Most of the interviews were conducted in the participant's homes. This choice of location was predominantly dictated by their state of health and, in particular, their general lack of mobility. There were three exceptions to this rule. In one case, the participant and I had struggled hard to find a suitable date, time and location for an interview. When, by coincidence, she found herself in the vicinity of my residence, we jumped at the fortuitous opportunity finally to conduct our first interview. In the remaining two cases, the participant's own residential situation did not allow an interview to be conducted without hindrance and interference. We decided it best to conduct both interviews in the quiet and privacy of my residence.

Interestingly, Finch (1984: 74) notes that, in an interview setting where one woman "visits" the home of another woman, the interaction may easily assume the character of an intimate conversation. The participant may feel quite comfortable with this precisely because the researcher is present as a friendly guest, not an official inquisitor. In effect, "the model is... an easy, intimate relationship between two women" (Finch 1984: 74). Whether this indeed proved to be the case will be revealed in Part V.

Recording of interviews

In recording interviews, I had two options: note taking or tape recording. I chose tape recording.

Note taking, as Weiss (1994: 52-53) points out, tends to simplify and flatten participants' speech patterns. The conversational spacers (for instance, "you know what I mean") are not recorded in note taking. So are participants' false starts, stray thoughts and parenthetic remarks. As notes can never capture exactly what happened during an interview, the very vividness of the encounter disappears. What is more, note taking inevitably enmeshes the action of recording with the action of editing, leaving the researcher with no way of knowing

what changes had been made to participants' actual comments. What is more, there is no way for the researcher to determine how great an influence his or her own expectations and perceptions had played in what was heard, recalled and noted. With this as background it was clear that note taking was not a desirable option in this study.

Some (cf. Laslett & Rapoport 1975: 972) would argue that the mere presence of a tape recorder serves to remind the participants that they are indeed being recorded and that this may inhibit and constrain their expression of experience. Although I acknowledge this possibility, I wanted to learn more about how participants saw and responded to events and situations than simply to learn about the events and situations themselves. I therefore had to rely on a tape recorder to capture the important nuances and complexities of speech which I surely would have missed had I simply taken notes. Tape recording thus presented the most appropriate option.

In accordance with Weiss' (1994: 53) experience I found that by using a tape recorder (and, hence, not relying exclusively on note taking), I could more directly attend to the participants and their descriptions. I had more freedom to concentrate and become involved with them in the dynamic of the interview situation. I did not have to worry about "getting it all down", or carefully quoting their every word. I could now rely on the tape recorder to produce the material for a more accurate transcription of the interview. The part I played during the interview, at least on a verbal level, would also be more open to scrutiny in such a transcription.

Finally, it is important to note that the decontextualised transcriptions based on tape recordings do not represent a complete record of the non-verbal communication and interaction between researcher and researched. Indeed, much happened before and after an interview that was not tape recorded. The importance of these informal and non-verbal elements of interaction can never be under-estimated (cf. Laslett & Rapoport 1975: 972). As a result, a degree of note taking was inevitably required to record these elements. Such note taking typically occurred directly after or at least very soon after an interview had been concluded.

Interview process: How did it proceed?

Preparation

Thorough preparation was required to accommodate the desired design features throughout the interview process. In fact this meant, as Kvale (1996: 126) predicted, that a substantial part of the investigation had taken place before the tape recorder was turned on in the actual interview situation. The issues which needed to be addressed at this stage included acquiring a thorough pre-knowledge of the particular field of research, formulating a clear purpose and direction for the interview process, and being sufficiently familiar and at ease with the chosen interview technique and its application. In short, I needed to be informed, focused and proficient.

Approaching the topic

At the start of the interview process participants were introduced to the research project. This introduction, also referred to as a "briefing" (Kvale 1996: 127), established the context of the interview, defined its purpose, and outlined its course. At this stage participants were also offered the opportunity to clarify or question any aspect of the research (cf. Appendix D). These first steps into the interview process were, as Kvale (1996: 128) recognises, absolutely decisive. It was here where the participants formed their first impression of me before allowing themselves to talk freely and expose their experiences to this "stranger". It was also here where it was most important for me to show respect, interest and understanding for whatever concerns the participants voiced.

Defining the exact boundaries of my research topic complicated this introductory process. If I defined it too broadly, the participants might have felt left in the dark as to the precise purpose of their contribution. If I defined it too narrowly, it could inhibit the participants from formulating their experiences in their own way, and raising topics which would appear to them to be beyond the defined scope of research. I also realised that, once the boundaries were defined, it might be difficult to inquire into aspects of participants' lives not clearly falling inside these boundaries (cf. Lee 1993: 102-103). With these concerns in mind, I set out to define the research topic in a manner distinct enough to give direction and show purpose, but general enough to allow freedom and inspire exploration (cf. Appendix D).

A concern for the most appropriate definition of the research topic also brought into focus the question of informed consent. Although I had tried to be as clear and farsighted as possible in

introducing the study to the participants, there was no way for me to predict all that would transpire. The element of uncertainty was seriously increased by the fact that this study concerned a field of research about which very little was known, and it thus demanded considerable flexibility in both purpose and design. Change and adjustment came with the territory. Neither my participants nor I could have anticipated everything that the study eventually encompassed (cf. Kvale 1996: 112-113; Lee 1993: 103). All that I could do was to inform the participants as comprehensively as possible about the foreseen contingencies of the proposed study and to strongly emphasise its distinctly flexible (and therefore slightly unpredictable) nature. On this basis, they consented to participate.

Listening

Following the advice of Devault (1990: 102-104) and Opie (1992: 59), I aspired to listen attentively to the participants' descriptions as they constructed them. The general framework I followed while doing so was to check whether I was clear on all relevant aspects: Do I know what led to the experience? Do I have a detailed understanding of the experience itself? Do I know who else was involved in the experience? Do I have an understanding of how the participant felt at the stage? Do I have an understanding of how the participant thought about the experience? Do I know what followed the experience?

While listening, I deliberately listened for what Weiss (1994: 77) calls "markers". These are references to an important event or state of feeling often made in passing by a participant in the course of talking about something else. When the opportunity came, I attempted to follow up on these markers, usually by saying something like, "you mentioned earlier that... can you tell me more about it?" This approach generally worked towards the development of a more elaborate description, often yielding significant insight.

In addition, as Devault (1990: 102-104) and Opie (1992: 59) recommend, I not only listened to what was said, but also to what was *not* said. As I noted the "missing" elements, I also became aware of the ambiguous, the paradoxical, the contradictory and the marginal. While such elements might be regarded as quantifiably insignificant, their presence (or absence!) time and again led me to regard the participants anew, to hear their accounts in novel ways, and so to develop a more intimate understanding of their experiences.

My guiding concern throughout was to judge if what was being revealed, added greater understanding. In other words, as I listened intently to my participants the pertinent question in my mind was, "Does this material help to illuminate lived experience in any area of the present study?" This was no easy judgement, especially not during the early stages of research when everything disclosed to me appeared relevant to the study. Generally, whenever I was overcome with doubt, I allowed the description of an experience to develop. In this way I could include for analysis not only what was expected and run-of-the-mill, but also what was unanticipated, surprising, incredible, and even inconceivable.

Managing transitions

At certain stages during a research interview it became necessary to redirect our interaction at obtaining greater detail about particular areas of interest. Here the direct management of transitions from one area to the next became crucial.

At every transition I was concerned not to fluster or alarm participants by introducing a new area of interest simply out of the blue. I rather tried to follow their associations as far as possible. In the process, I reminded myself that through my responses (however subtle or seemingly insignificant) I had considerable influence over the direction in which these associations could go. Admittedly a more direct approach was sometimes required, especially in those instances where a participant strayed off at a tangent with no hope of spontaneous return. In such cases I tried to warn participants of a coming reorientation by summarising or rephrasing what had been said, thereby drawing the participant back and drawing that part of the conversation to a close. I would then mention that there was still another area of experience I was very interested in. In this way the impending reorientation was introduced and alarm avoided.

Managing emotions

At times during the interview process it was clear that participants experienced intense distress evoked by their very participation in the interview. Such distress stemmed from the fact that participants were ill – often desperately so. For them there were moments when it was excruciatingly difficult to talk, let alone sit up straight, for any extended period. Their distress also became most acute when sensitive, stigmatised or otherwise problematic areas of experience were broached, as well as when they painfully struggled to find words through

which to give expression to such experiences (cf. Brannen 1988: 553). Often the resulting accounts were shrouded in emotionality.

Such distress and emotion needed to be managed throughout the course of the interview process. Here, in following Brannen's (1988: 559) directive, I tried to remain consciously aware of the ways in which I attempted to manage participants' distress as well as of my motives for doing so.

So, when participants struggled, became distressed, and fought to hold back their tears, I had to consciously decide how to respond. Often at such times all I could undertake was the difficult task of enduring and sharing the pain of the participant. In line with Cannon's (1989: 73) approach, I often felt that the less I said the better, since nothing I could say could possibly change their situation, regardless of how much I longed to make it better. I limited myself to providing much needed tissues, making a soothing pot of tea, providing some form of comforting physical contact such as holding a hand, or a combination of these whilst remaining more or less quiet. Through doing so, I wanted to ensure that participants knew that they could take all the time they needed to recover, settle down, and work through the incident that was evoking such sadness and discomfort. I needed them to know this because I realised that it was only when they had personally worked through such experiences that they would be able to construct them with me in and through our conversation.

Regardless of all my noble intentions, I still found it extremely difficult to bear the distress and emotion evoked in my participants by my study. I found it a genuinely stressful and, on occasion, a severely tormenting experience to interview ill participants about highly sensitive and disturbing experiences (cf. Lee 1993: 107).

Termination

I was intent not to violate the participants' worlds, their very lives, through the consequences of the study. Hence, in the final interview I directly asked them to share with me their impressions of the research (cf. Appendix E). How did they experience it? What did they think or feel about it? How did they experience me? Did they think there were any mistakes made? How could it have been done differently? What did they hope would happen to the study and its results? Through this process, called "debriefing" by Kvale (1996: 128), I hoped to give participants ample opportunity to express and work through any doubts, anxieties,

hostilities, and reservations that the interview process might have elicited (cf. Laslett & Rapoport 1975: 973-974). In addition, I also used the opportunity created by the "debriefing" to assure participants of the unique value of their personal contribution to the study.

My intent not to violate participants' worlds also required me to explain as well as I could what would happen next, how I would go about working with the data, and how the findings would be published. Here, I mentioned the thesis as the obvious form of publication and also indicated that articles concerning pertinent aspects of the study could appear in reputable academic journals. I also promised each participant a copy of my the thesis which was, after all, produced as a result of their combined contribution. This gesture was very well received.

Conclusion

This study was directed towards an intimate understanding of human experience. The development of such an understanding relied upon the rich descriptions of lived experienced constructed with participants through our inter-active relationship in the context of the in-depth interview. In terms of both its design and its process the in-depth interview was geared towards the attainment of such descriptions – descriptions without which this study would not have been possible.

Admittedly, actual interview conditions did not always obey the interview design and process described above. But like Cotterill (1992: 602) I believe it is quite indefensible to differentiate between participants, let alone eliminate a participant, purely on the basis of what is considered to be a "good" or "bad" interview situation. Instead, I accepted that this study depended upon the cooperation of the participants, and that the onus rested on me to adapt to the participants' unique circumstances and make the best of the sometimes less than ideal interview conditions.

The Tennessee Self-Concept Scale (TSCS)

Towards the end of the first interview every participant was requested to complete the Tennessee Self-Concept Scale (TSCS) as developed by Fitts (1964).

The use of this measurement was geared to contribute to a multi-dimensional perspective on the ME sufferer's experience of illness and, in particular, of Self. After all, it has been shown that a self-concept engendered by a stigmatised illness, such as ME, may directly influence the sufferer's experience of the particular illness (Weinberg et al. 1994: 23-25). Following the advice of Strauss and Corbin (1990: 18-19), I also believed that the use of the TSCS could provide both structure and validation to the data collected through more qualitative methods.

My reason for choosing the TSCS will become more apparent as the nature of this instrument is considered.

Development

Roid and Fitts (1964: 1) explain that the development of the TSCS was based upon the theory that an individual's self-concept influences much of his or her behaviour and also directly relates to the individual's personality and state of psychological well-being. Fitts therefore proceeded to develop the TSCS in order to meet the need for a self-concept scale that would be "simple for the respondent, widely applicable, and multidimensional in its description of self-concept".

Fitts began the developmental work on the TSCS with the Tennessee Department of Mental Health in 1955. According to Roid and Fitts (1964: 53), the first step in the development of the scale was to compile a large pool of self-descriptive items. The original pool of items was derived from a number of existing self-concept measures as well as from written self-descriptions produced by patients and non-patients. After considerable study, items were classified into a two-dimensional, 3 x 5 scheme of rows and columns. After items were edited, seven clinical psychologists classified them according to the 3 x 5 scheme and judged each item as to whether it was positive or negative. The final 90 items to be included (divided equally as positive or negative) were those on which the judges reached perfect agreement. The final 3 x 5 groupings were then used to construct the Row and Column scores of the TSCS. The remaining 10 TSCS items comprise the self-criticism score.

Standardisation

Roid and Fitts (1964: 56) explain the process by which the TSCS was standardised: "the original standardisation group included 626 participants from various parts of the United

States, with ages ranging from 12 to 68. The group was composed of an approximated balance of males and females, blacks and whites, representatives of all social, economic, and intellectual levels, and of educational levels from sixth grade through the doctoral level. Participants were found through high school and college classes, employers at state institutions, and various other sources". Roid and Fitts (1964: 56) believe that this original norm group has been shown to be reasonably representative.

Based upon the norm group, as well as numerous subsequent independent investigations, Roid and Fitts (1964: 57-63) established that the effects of such demographic variables as sex, age, ethnic, education and intelligence were small and so accounted for very little variance in TSCS scores.

In addition, Roid and Fitts (1964: 66) found that repeated measures of the same individuals over long periods of time revealed a remarkable similarity of TSCS profile patterns. The implication is that an individual's self-concept is so fundamental that is does not readily change even though a person begins to feel and act differently. There is, however, considerable evidence that individual concepts of Self do change as a result of significant experiences. According to Roid and Fitts (1964: 82-83), the TSCS is capable of reflecting such changes both validly and reliably.

Indeed, throughout their discussion, Roid and Fitts (1964: 65-90) highlight both their own and independent evidence which testify to the reliability and validity of the TSCS as a scientific measurement of self-concept.

Administration

The TSCS is a pencil and paper questionnaire consisting of 100 self-descriptive statements which the participant uses to portray his/her own picture of him/herself. In the process, the participant rates each statement on a scale of 1 (Completely false) to 5 (Completely true) according to how descriptive the statement is of his/herself. Most individuals will complete the questionnaire in 10 to 20 minutes, provided that they are 13 years of age or older and can read at approximately a forth-grade level (Roid and Fitts 1964: 1).

Two versions of the TSCS are available: the hand-scorable and the computer-scorable. Both versions use exactly the same test items. In this study the hand-scored version was used. This

version can be scored and profiled in two ways – using Form C (the Counselling From) or Form C & R (the Clinical and Research Form). For this study Form C was used. This choice was influenced by the fact that I did not need an extensive background in psychometrics and psychopathology to interpret From C results, and that it was appropriate to discuss the results with participants. Form C provided 14 different scores for each participant. Roid and Fitts (1964: 3-4) present a brief description of each of these scores which is summarised in Table 4.1 below.

For hand administration and scoring of the TSCS, the re-usable Test Booklet and the Revised Answer-Profile Form were used. To administer the TSCS, participants were given the TSCS Test Booklet and the Revised Answer-Profile From. The scale is essentially self-administering and requires little explanation beyond what is provided on the Text Booklet. Nevertheless, in an attempt to ensure the utmost clarity and comprehensibility, I did explain the procedure verbally to each participant (cf. Appendix F).

In following the directions provided by Roid and Fitts (1964: 8-18), I hand scored participants' responses. I proceeded to transfer the raw scores from the Work Sheet to the Profile Sheet which was used to provide a graphic display of participants' TSCS scores. Each participant's scores were interpreted comparatively, noting in particular the individual scores that were either extremely high or low in relation to each of the other scores. Individual item responses to statements concerning such particularly high or low scores were also investigated. Information gained in the process was pursued in the second interview session. During the latter, the TSCS Profile, as a simple graphic representation of a participant's responses, was shared with each participant (cf. Appendix G for an example of such a profile).

In summary, then, the TSCS can be regarded as a well-standardised, widely applicable measure that is easy to complete, easy to interpret, and easy to share. In this study it was used to attain an indication of the self-concept held by participants and through this to explore how this concept might both reflect and illuminate their experience of illness.

Table 4.1 TSCS score description

Score	Sub-score	Description
Self-criticism		The individual's openness to and capacity for healthy self-criticism
Total score		The individual's overall level of self-esteem – the most important TSCS score
Row scores		The individual's internal frame of reference
	Row 1: Identity	The individual's perception of his or her identity
	Row 2: Self-satisfaction	The individual's satisfaction with the perceived self-image
	Row 3: Behaviour	The individual's perception of his or her own behaviour
Column scores		The individual's external frame of reference
	Column 1: Physical Self	The individual's view of his or her body, state of health, physical appearance, skills and sexuality
	Column 2: Moral-ethical Self	The individual's moral-ethical frame of reference in terms of moral worth, relationship to God, feelings of being a 'good' or 'bad' person, and satisfaction with his or her own religion
	Column 3: Personal Self	The individual's sense of personal worth, feeling of adequacy as a person, and self-evaluation of the personality apart from the body or relationship to others
	Column 4: Family Self	The individual's feelings of adequacy, worth, and value as a family member
	Column 5: Social Self	The individual's perception of Self in relation to others and sense of adequacy and worth in social interaction with other people in general
Variability scores		The amount of inconsistency from one area of self-perception to another.
	Total variability	The total amount of variability for the entire record
	Column variability	A summary of variation within columns
	Row variability	A summary of variation across rows
Distribution		A summary of the pattern of the individual's responses as distributed across the five available response options for each TSCS items as they appear on the Answer Sheet

The autobiographical sketch

For Daly (in Plummer 1983: 82), "a man's life is to him the most obvious and overwhelming of all realities". A full exploration of this "reality of all realities", called for a method that would expose a person's intensely subjective experience of being. To this end, I opted to incorporate the autobiographical sketch into the methodological design of this study.

The autobiographical sketch was considered akin to Redfield's (in Plummer 1983: 14) conception of a "human document". In this view the autobiographical sketch constitutes a document "in which the human and personal characteristics of somebody who is in some sense the author of the document find expression, so that through its means the reader of the document comes to know the author and his views of events with which the document is concerned". The central thrust of the autobiographical sketch is to enable the voices of participants to be heard on their own terms.

To facilitate a more comprehensive understanding of the nature, use and value of the autobiographical sketch within the bounds of this study, I will now consider its distinguishing emphasis both on the subjective and on process.

A doorway into the subjective

The autobiographical sketch is, as Plummer (1983: 14) acknowledges, "a purely subjective account". It is primarily concerned with the subjective and, in particular, with the subjective perspective of the participant. This "subjectiveness" does not mean that a sketch should be considered untrue or even "unscientific". What matters more than the exact particulars of the account, more than its "objectiveness", is "the facilitation of as full a subjective view as possible" (Plummer 1983: 14). Where the autobiographical sketch escapes entrapment by the objectivist belief in "the one truth", it opens the way towards a truly full exploration of the subjective realm.

Within this subjective realm, the autobiographical sketch permits the attainment of insight into the ways in which participants interpret, make sense of and give meaning to their own lives as well as to the world around them. According to Plummer (1983: 65), such insight allows the researcher to discern the often unique confusions, ambiguities and contradictions that characterise the continuous flow of participants' lived experiences. It is easy to see why

Plummer (1983: 82) concludes that "the central value of life documents – and the job they can best do – lies in the tapping of ordinary, ambiguous personal meanings".

Thus, the uniquely subjective perspective attained through the use of the autobiographical sketch allowed me not only to seriously consider, but also to become intimately familiar with participants' concrete lived experiences (Plummer 1983: 65 & 72). Because I was thus able to root my understanding firmly in the empirical world being studied, I could avoid the risk of unfounded speculation, the risk of simply being wrong.

A testimony to process and history

In addition to showing the way into the subjective, the autobiographical sketch contains a clear emphasis on process and history. Hence, it offers incisive insight into the ever-changing nature of human experience (Plummer 1983: 68).

Process is, in fact, a particularly difficult quality to capture in research because all research – qualitative research included – invariably has to amputate, select and organise materials. This is done from a particular point of view or perspective. For Plummer (1983: 68-69), the perspective which governs the use of the autobiographical sketch is one of totality: "the totality of experience". This is a totality which necessarily weaves between biological bodily needs, immediate social groups, personal definitions of the situation, and historical change both in the participant's own life and in the outside world. The autobiographical sketch allows the researcher to grasp a sense of this totality of a life, admittedly not as an undiminished whole, but at least to the extent that it is concerned with the field of study in question.

The perspective of totality that distinguishes the autobiographical sketch leads the way, then, to a consideration of process and of history. As Bogdan (in Plummer 1983: 69) explains, such a perspective does, after all, offer "a fuller understanding of the stages and critical periods in the process of development. It enables us to look at subjects as if they have a past with successes as well as failures, and a future with hopes and fears. It also allows us to see an individual in relation to the history of his time, and how he is influenced by the various... currents present in his world. It permits us to view the intersection of the life history of men with the history of their society, thereby enabling us to understand better the choices, contingencies and options open to the individual". Thus, through its unmistakable perspective of totality, the autobiographical sketch endorses the hope for greater insight into the changing

meaning of participants' lives as they move not only through history in general, but also through the history of their illness in particular.

Conclusion

It is clear that I could not consider this study to be sufficiently appropriate without the use of the autobiographical sketch. Indeed, I found that the inclusion of the autobiographical sketch into the methodological approach of this study promised access to what Plummer (1983: 67) calls the "human coefficient". It would illuminate the ways in which participants constructed and gave meaning to their own lived experiences, and it would inspire understanding.

Consequently, at the end of our first interview session and after the completion of the TSCS, participants were requested to compose an autobiographical sketch describing their own experience of ME (cf. Appendix H). To assist them in doing so, I offered a brief guide consisting of a limited number of questions to which they could respond in whatever way seemed meaningful to them (cf. Appendix I). These sketches were to reach me before our next meeting. I anticipated that the autobiographical sketches produced by participants, in combination with the material developed in the first interview as well as the TSCS results, would provide a powerful foundation for the second and final round of in-depth interviews. This expectation, indeed, reveals still another value of the autobiographical sketch: its huge potential to compliment other methods within a sensibly designed methodological approach.

Conclusion

This study was directed towards an intimate understanding of human experience. The development of such an understanding relied upon the rich descriptions of lived experiences co-constructed with participants through our interactive relationship. This relationship was distinctly structured according to the opportunities and limitations introduced through the in-depth interview, a self-concept questionnaire and the autobiographical sketch. Together, these instruments not only worked in complementarity to stimulate descriptions of the world of ME suffering, but also directed the very form and content such descriptions could assume.

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Chapter 10

Transformation of information: Dealing(s) with the data

In this study I was explicitly concerned with the relational unfolding of rich descriptions – descriptions which construct unique social realities, which tell about participants' worlds as these were co-produced through our interaction. Yet, once I stepped out of the research encounter, such descriptions became subject to my manipulation as they were transcribed, analysed and interpreted. Chapter 10 describes the ways in which I manipulated – and indeed transformed – the data to produce a credible description of the social world being studied.

Transcription

In this study the tape recordings of all interviews as well as of one autobiographical sketch were transcribed. Such transcription encompassed the transformation of interpersonal conversation into a literary style that would facilitate the communication of participants' stories to others (Kvale 1996: 166). Like Kvale (1996: 163) I had to recognise that such a transformation of speech from the oral to the written mode inevitably involved a series of judgements and decisions.

The challenge

Kvale (1996: 129) asserts that the lived interview situation, with participants' voices as well as their facial and bodily expressions accompanying their every statement, provides a much richer access to the meaning they construct than the transcribed text alone. Still, in order to communicate the meaning of participants' stories to potential readers, it is necessary to transform the interpersonal interaction of the interview situation into a written transcript.

The transcripts are not identical to the conversational interaction of the interviews themselves. In fact, unlike that which had transpired through the interviews, the resultant transcripts can never be the "rock-bottom" data of research. And they are certainly not copies or representations of some more "original reality". On the contrary, transcripts are what Kvale (1990: 167) calls nothing but "decontextualized conversations", artificially constructed for the purpose of communication. They are "abstractions, as topographical maps are abstractions

from the original landscape from which they are derived" (Kvale 1990: 165). Thus, while transcripts attempt to describe interview situations and their content, they can never fully represent what had actually transpired.

Why is this so, why can transcripts be nothing more than abstractions? Because the process of transcription "freezes" a living, ongoing conversation into a written text. Thus "the words of the conversation fleeting as the steps of an improvised dance, are fixated into static written words... The words of the transcripts take on a solidity that was not intended in the immediate conversational context. The flow of conversation, with its open horizon of directions and meanings to be followed up, is replaced by a fixated, stable written text" (Kvale 1996: 167). In the process, through "freezing" conversation into static text, context is greatly diminished. The temporal, spatial and social dimensions of the interview interaction are no longer immediately given as they were in the interview itself. Consequently, where the interpretation of meaning depends on context, the basis of such interpretation is gravely impoverished. This once again shows that transcripts can never be accepted as the fundamental data of a study. They would simply fall far too short to produce any significant insight or understanding.

Still, it is necessary to recognise that without transcripts, even frozen as they are in all dimensions, there would be no opportunity of repeated inspection. There would be no way (for either the researcher or anyone else) to take another look at what had happened during a conversation with a participant. This does not mean that transcripts must be regarded as "the fundamental verbal data". Instead, it simply means that transcripts can be accepted as a means of evoking and reviving for the researcher the personal interaction of the interview itself. It is not the basis of all future analysis, but it can undoubtedly aid and support it.

The actual doing

In following the example set by Devault (1990: 109), I deliberately attended to the details of my participants' speech in the process of transcription.

In the process, I developed the rudiments of a system for preserving some of the "messiness" of everyday talk. I systematically transcribed and indicated details of emphasis and pause. I included "false starts" (when a sentences is started, abandoned, and started again), particular emphasis, periods of silence and even apparently superfluous phrases. I inserted an ungrammatical "..." to indicate hesitation and pauses in mid-sentence and between sentences.

I included most of the "mmm"s, "uh"s and "you know"s interjected by participants. I indicated smiles as well as outright laughter. I recorded deep sighs and smaller "out-of-breaths" which often signalled an emotional experience. I also transcribed the often confusing and highly complicated process of self-correction.

In these ways, I recorded more of the inelegant features of participants' talk than is customary. As a result of this somewhat unorthodox approach, I was able to retain at least some of the distinctiveness of participants' verbal expression (and construction) of their lived experience. Indeed, had I not included these details, had I edited these exchanges and freed them of the odd and "non-essential" noises of talk, I would have reworked their construction and, hence, their meanings. Then, "the transcript would move forward in an orderly and formal manner. But the dynamic construction of what was said would be gone" (Paget in Devault 1990: 109). If the dynamic construction of participants' experience were to be lost, so too would the building blocks of the subsequent analysis. It was therefore critically important for this study to preserve as much detail as was possible.

Aside from the detail of speech itself, included into every interview transcription were also brief pre- and postscripts. In the prescript, I noted when the meeting started, what we talked about before the "official" interview commenced, the nature of our interpersonal interaction, my experience and impression of it, my hopes and fears for the interview that lay ahead, and how the interview then did actually start. In the postscript, I similarly noted what had transpired as we reached the end of our encounter, what was said once the tape recorder had been switched off, the nature of our interpersonal interaction, my experience and impression of it, my perception of the interview as a whole, and how our encounter then came to a close. Like Kvale (1996: 129), I regarded these immediate impressions as invaluable, especially in offering a much-needed context for the later analysis of transcriptions.

Still, I have to agree with Devault (1990: 108) that no matter how complete a transcript it cannot preserve all the details of a participant's speech, let alone of the dynamic interpersonal interaction marking a research encounter. What is more, it must also be recognised that no single transcript can be regarded as the most "true" or most "objective" transformation of speech and interaction into a written text (cf. Kvale 1996: 166). There is no one perfect way of doing this. And there is certainly no easy way.

So, then, armed with the counsel offered by Devault and Kvale, I set out to personally transcribe all interviews and one autobiographical sketch. By doing so I tried to ensure that the countless details I regarded as pertinent to the analysis would be included. This rather stressful and acutely tiring endeavour took an almost unbelievably vast amount of time. On average, one hour of interviewing took more or less eight hours to type verbatim (remember: it was my first time!). Eventually, it added up to about 250 hours of dedicated transcription. Despite the all but overwhelming nature of this task, I continue to consider every transcript that was produced worth the effort, time and dedication it had demanded.

The presentation

In Parts IV and V examples of transcribed talk will be discussed. In choosing how to present these examples, I was faced by two opposing positions (cf. Blauner in Weiss 1994: 192).

The preservationist approach

On the one hand, there is what Weiss (1994: 192) calls the "preservationist" approach. The basic idea here is that literally every single element in a participant's expression – be it non-standard grammatical constructions and pronunciations or seemingly confused narrative – has value as communication and, therefore, demands inclusion into any presented interview excerpt. This demand for total inclusion is linked to the notion that to reach understanding of a participant's experiences necessitates a focus on the very specific ways in which these are related and construction. Correspondingly, any exclusion of such intrinsic and essential elements of the interview encounter would introduce distortion and misrepresentation of the interaction, the speech, and the speakers.

As an aside, the preservationist approach also requires that anyone wishing to evaluate the claims and interpretations that the researcher has made about sections of transcript, wants to do so without being "handicapped by information lost through judgements about what is extraneous" (Potter 1996: 9). That is, only when all information is presented as part of a transcript can research (and the researcher) be fully open to outside scrutiny.

Thus, arguments in support of the preservationist approach do not demand that detail be preserved in the presentation of transcripts simply for the sake of an empiricist flourish in order to demonstrate completeness, conscientiousness or rigour (all of which it can do, of course) (Potter 1996: 9). For supporters of this approach, it is more a question of preserving

original speech, pristine and without any editorial interference, so that the participant's construction, indeed, the participant's Self, can be adequately represented. "Anything else distorts... Anything else is playing with the evidence, no matter how benign the intent" (Weiss 1994: 193).

The standardisation approach

The argument for standardising excerpts from interview transcripts is, as Potter (1996: 8) and Weiss (1994: 193) explain, that non-standardised speech both distracts from content and impedes intelligibility. That is, far from enriching insight, a too faithful rendering of a participant's speech may actually strike the reader as complicated, affected and annoying. Instead of being able to understand the meaning of a participant's construction at first glance, the reader would now have to struggle through "unnecessary" detail to puzzle out the intended meaning.

Mindful of this possibility, the standardisation approach encourages the researcher to simplifying a transcript, thereby stripping it of all extraneous elements. In this sense, speech needs to be "cleaned up" so as to be more readable as well as easily accessible to all those not involved in the original situation (Potter 1996: 8).

The compromise

Like many other investigators (cf. Weiss 1994: 193-194), I opted for a compromise. So, for the interview excerpts presented in the following chapters I had made those modifications which I believed would make the excerpts easier to grasp but without affecting the participant's meaning. I permitted myself to eliminate words, sentences, and paragraphs (also often my own questions) – all in order to achieve a more compact statement. However, I never changed or added a word. Also, every effort was made to preserve the participant's phrasing and characteristic mode of expression.

Furthermore, although aware of advice by researchers to omit "nonsensical" noises such as "uh-huh" and "mmm" from quoted text (Weiss 1994: 196-197), I could not follow this advice blindly. Very often, such "distractive" utterances and phrases served a distinct purpose within communication. In this study it was, for instance, important to indicate when participants were struggling to express their experiences either because of a lack of vocabulary, or because they had not thought about the answer so intensely prior to our encounter, or because they were

beginning to suffer from the cognitive difficulties which set in with increasing fatigue. The only way to do so was through the inclusion of participants' interjections. So, far from being simply unnecessary distractions, such interjections helped to clarify meaning and made a valuable contribution to an understanding of the text. In addition, they often helped to establish a sense of speech as a co-constructed product of contextualised interaction. I therefore opted to retain such information, provided that it did not pose a major obstacle to the intelligibility of the text in question.

In addition, in the name of coherence, I attempted a fair amount of reorganising of the participant's description. For instance, if a participant develop a theme (such as, "I hate the illness"), went off to something else, and then returned to the original theme, I would bring together all the material dealing with the original theme. It is, after all, asking quite a lot of a reader to sort out scattered thematic material. Usually, when portions of speech had been omitted from a text, it would be indicated using ellipsis points. Yet, like Weiss (1994: 198), I have rarely found this exceptionally useful. Ellipsis points were rather generally used in this study to indicate the ebb and flow, the pause and continuance, of the human conversations in which meaning was constructed.

Thus, I admit that in terms of my compromise in the presentation of interview transcripts, I did make modifications. Every one of these was done with the clear intent of enhancing the communicability of text, and never to be to the detriment of the participants or their constructions.

Conclusion

In all my transcriptions I endeavoured to remain as faithful as possible to the participant's choice of words, sentence structure, and manner of expression. While mindful of the fact that no amount of faithfulness can produce a complete rendering of the interview situation itself, I could not deny the fact that sensitive transcription constituted the best (if not the only) way of both illuminating and communicating the participants' constructions. Hence, in these transcriptions as well as in the presentation thereof, I was ceaselessly trying to offer a just and intelligible representation of the participants' stories.

Analysis

Dey (1993: 30) explains that the word "analysis" "derives from the prefix 'ana' meaning 'above', and the Greek root 'lysis' meaning 'to break up or dissolve'. It is a process of resolving data into its constituent components, to reveal its characteristic elements and structure. Without analysis, we would have to rely entirely on impressions and intuitions about the data as a whole. While our impressions and intuitions certainly have their place in analysing data, we can also benefit from the more rigorous and logical procedures of analysis".

These procedures for analysis need to be explicated. Kvale (1996: 207) stresses that, in contrast to the readers of a critic's analysis of a poem, the readers of a research report (such as this text) will not have access to the tape recordings and the often many hundreds of pages of material on which the researcher's interpretations are based. The reader of a report has to depend on the researcher's selection and presentation of the research material. In the light of this it is not surprising that Kvale encourages the researcher to thoroughly explicate the procedures for analysis, including his or her own perspective on the material. The researcher should, so to speak, put his or her cards on the table for inspection. Only then does the reader become able to retrace and check the steps of analysis. Only then can a reader adopt the viewpoint of the researcher and so look at the data through the eyes of the researcher.

The most productive way by which I can readily describe the perspective I adopted and the procedures I applied in the process of analysis in this study is through an analogy. With reference to Dey's (1993: 40-47) discussion, the analogy I find best to apply is the one of a jigsaw puzzle. In the process of analysis described below, all the pieces of the data puzzle were cut out in such a way that they could again be put together to produce a new picture in the form of my final description.

Cutting out the puzzle

I found that the data gathered in the course of the research process represented an almost seamless aggregation of material. From this aggregation I was able to cut out all the bits of my jigsaw puzzle. Once cut out, I needed somehow to re-organise all the pieces of the puzzle. Hence, I embarked on a process of classification whereby, based on an assessment of its characteristics, I assigned every piece to a particular category. So I became able to discern, as Dey (1993: 40) explains in jigsaw puzzle terms, that "this bit is a corner, that one an edge, this blue bit is sky, that brown bit is earth, and so on". Gradually, as in a jigsaw puzzle, all the blue

bits together made the sky, the brown bits the earth, and the green bits a forest. The categories through which I had initially organised the pieces – flat-edged, blue, brown and green – now led towards a new concept-based classification – sky, earth, forest – in terms of which I could proceed to describe an overall picture.

This conceptual process of classification, then, clearly involved two activities. I had not only cut out the data into bits and pieces; I had also assigned these to different categories and eventually to different concepts. So, all the bits "belonging" to a particular category were brought together and united under one concept. As the process became more focused, I was able to discriminate more clearly between the criteria for allocating material to one concept or another. The boundaries between concepts were defined more precisely. New concepts were created. Some older concepts were subdivided. Others were subsumed under more abstract concepts. Every one of these concepts was firmly based upon the participants' descriptions of their world and, in combination, geared to reflect an intimate understanding of this world (Dey 1993: 45; Rubin & Rubin 1995: 226).

Thus, faced with the ever-increasing mass of data, I proceeded to cut out the different pieces of my jigsaw puzzle. These pieces were organised, classified, and united under a set of concepts. These concepts not only corresponded to the different facets of the social reality under study, but also provided a preliminary framework through which the pieces of the puzzle could again be brought together in an analytically meaningful way (Dey 1993: 45).

Putting it together again

As Dey (1993: 40) notes, "the only point of taking the puzzle apart, of course, is to find a way of putting it together again". In other words, cutting out the jigsaw puzzle and organising these pieces into concepts did not constitute an end in itself. It served an overriding purpose: to produce a picture. So, while classification had provided the basic concepts, these concepts now had to be meaningfully connected to produce a new picture.

In order to establish such meaningful connections, I looked to Dey (1993: 47) as well as Rubin and Rubin (1995: 226-227) for advice. They suggest that while working through the by-now-classified-data, the researcher should be sensitive to regularities, variations, and singularities, as these are very often indicative of larger associations. By studying such associations, I was able to weave different concepts into distinctive themes. These themes, which appeared to

explain or give insight into related issues, constituted the basis of my emerging understanding, of my new picture.

So the different parts of my jigsaw puzzle again came together. For me, as for Dey (1993: 40), the emerging picture that this development introduced represented a very important step towards defining the findings of this study. It did, after all, reflect an understanding infinitely clearer and more complex than any initial impression of the data might have intimated. In this sense, analysis involved much more than simply fitting the different pieces of the puzzle together; it involved the conception of something new, of something extraordinary, of something profoundly novel.

Conclusion

"Meaning is", as Dey (1993: 37) acknowledges, "always negotiable". This was particularly true in the process of analysis. For, unlike the impression that might have been created above, this process did not proceed in neat sequence. And it certainly did not constitute a static, one-dimensional process. Rather, the process of analysis occurred throughout the research process, in tandem so to speak, with every step of data collection. Hence, the resulting analysis was very similar in character since it both stimulated and was stimulated by the collection and investigation of data. Thus, while analysis was undoubtedly systematic, it was also very much continuous and iterative in nature. And it was these traits that conferred upon its product a unique measure of openness to change and to negotiation.

In addition, as the process of analysis was not static, so it was not neutral. In fact, it could not be. It was always analysis with a purpose (Dey 1993: 46). And the governing purpose was to develop a coherent (though not necessarily highly abstract) account that would serve to adequately address the research question of this study. Stated differently, the process of analysis I had followed was not just muddling through the mass of data. It was very clearly and very deliberately directed towards an overall purpose: to produce an in-depth understanding of the social reality under study. It is towards the production and presentation of this understanding to which I now turn.

Interpretation and description

In the process of analysis, I have broken down the data puzzle in order to re-organise and classify it, I have created and employed the resulting concepts, and I have established the inter-connections between these. This had provided the basis for the construction of a fresh description.

As a production

Dey (1993: 30) feels that description forms the very bedrock of science. What is more, such description is exclusively the responsibility of the researcher. The data and its analysis provide the basis for the description, but it does not dictate the description, let alone produce it on its own. But how does a researcher go about producing a description of the research and its findings? Moreover, how did I go about doing so?

Through description (paradoxically) researchers very often want to do more than describe; they wish to interpret, explain, and understand. In doing so, they go beyond the initial description, and transform the data into something it was not (Dey 1993: 30; Kvale 1996: 201). Like other researchers I also wanted to do that. I wanted to go beyond what was directly said and what was immediately apparent, beyond... into a reality of a different kind.

Creating (constructing) a reality

With my eyes firmly fixed on what lay beyond, I definitely did not attempt to locate and reveal "one true and real" meaning through the description presented in Part IV. I certainly did not regard research as mysteriously capable of offering "direct access to unadulterated provinces of pure meaning" (Kvale 1996: 226). Instead, I was more concerned with a relational unfolding of meanings – meanings which construct unique social realities, which tell about participants' worlds as these were co-produced through our interaction. Thus, whatever is presented in and through my description does not represent a revelation of some pre-existing meaning, but merely supports those meanings developed during the course of an interactive research process.

In this sense, the rendering of an account of the research and its findings was not simply a question of "reporting" or simply re-stating participants' views, accompanied by my own. No, description was a matter of production (Dey 1993: 237). Indeed, as Dey (1993: 242) stresses,

the term "findings" can be "grossly misleading, with its implication that we have only 'found' what was already in the data simply waiting to be discovered". If this were the case, qualitative work would be "as straightforward as collecting rubbish. And if we were to adopt this approach, rubbish is all we might be able to produce!" Far from rubbish collection, the description I produced was very much the product of the conceptual tools that I had used in its creation.

One very important set of conceptual tools which I had employed in the production of my description derived from the literary tradition of story telling. In other words, as I was describing the research process and human experiences it had studied, I was making use of the particular writing style and techniques entailed in telling a good story (cf. Dey 1993: 39). I summarised events, focused on key episodes, selected and developed themes, delineated roles and characters, and even set out a chronological sequence. Every one of these techniques of story telling was used to construct the most illuminating narrative I could. In doing so, my wish was to tell the story in the best way I knew because I needed to be convinced (at least in my mind) that there was no better way to present the understanding that has been reached, or to present the realities of the participants.

Revealing the journey

Through narrative structures and devices, I set out to produce a meaningful description of the interactively produced realities of the participants. For Dey (1993: 239) such a description, if really is a good story, becomes very much like a journey that allows readers to travel with the characters of the story through the intricacies of the plot, eventually reaching its final twist in the form of a conclusion.

To enable others to travel with me and my participants it was, as Dey (1993: 239) emphasises, imperative that I should reconstruct the journey which had led to the final conclusion. Of course, the original journey had included some blind alleys, a couple of u-turns, and even the odd short cut that turned out to be a long road. What was important to me in the reconstruction of my journey was not to include every such detour but that I had discovered along the way the "right" path leading to the final conclusion. I was, therefore, now in a position to mark out this path for those who wish to follow and arrive at the same conclusion.

This emphasis on the importance of revealing the journey taken in the description of the social world under study indicates that another researcher can look at the same data and come up with the same interpretation. Of course, as Giorgi (in Kvale 1996: 209) recognises, there is also the possibility that a different researcher can look at the same data, ask different questions, adopt a different perspective, and then come up with an entirely different interpretation. However, the point here is not so much whether a different interpretation of the research material can be developed – this possibility has already been acknowledged – but rather whether a reader, following the same journey articulated by me, can also see what I had seen, regardless of whether or not he or she is able to agree with me. Giorgi sees this as the key criterion for good qualitative research. For me, it is the very point and focus of Part V.

What is more, perhaps the different interpretations to which a study such as this one lends itself is not a weakness but rather, as Kvale (1996: 226) believes, a strength. The likelihood of different interpretations does, after all, demand of the researcher to thoroughly explicate the journey taken. This brings the researcher face to face with the challenge of explaining his or her own choices, actions and procedures to others. Should the researcher choose to live up to this challenge, this choice may very well promote both a more integrated interpretation and a more forceful description (Dey 1993: 237).

As a responsibility

As already noted, description is the responsibility of the researcher. For Brannen (1988: 552), an important part of this responsibility consists in the protection of participants in and through what is disclosed in the description of their world.

Disclosure and disguise

"What should be disclosed?" This is a central anticipatory issue when the results of research on a sensitive social reality are to be described and published. Implicit in this question is the requirement to choose to what degree participants should be disguised in order to protect them.

When disguise is at issue the use of pseudonyms immediately comes to mind. Here, it is worth noting, as Lee (1993: 185) does, that "pseudonyms have long been used in published reports to disguise research sites and research participants. Anonymity protects... those studied". While I acknowledge that the use of pseudonyms is certainly far from universally applicable, it indeed appeared necessary in this study. I had therefore selected – completely at random -

pseudonyms for the participants. This course of action was based on my belief that where participants could not be identified, they could not be harmed. By disguising the participant's identity by the use of pseudonyms I wished to steer them as far as was possible clear of all harm, embarrassment, exploitation and/or harassment.

In addition to the use of pseudonyms, I also had the option of changing more details where I deemed necessary (Lee 1993: 187). So, where it did not seem to matter much, I made whatever changes seemed useful for disguise – and these added up to few in number. For instance, where it carried very little importance, I preferred to drop a reference to a place rather than invent a substitute. While doing so, I was consciously aware of the risk of distortion and, hence, deliberately tried not to misconstrue the character of participant's lived experiences.

Thus, while telling the participants' stories, I wanted to ensure that they would not be recognisable to others. The changes made to this end were, in my mind, enough to provide disguise and thereby offer protection, but not enough to distort the very human elements that were so essential to their stories.

Self-censorship

Lee (1993: 187-188) recognises that researchers may engage in partial self-censorship by deliberately "choosing to omit specific items of sensitive information from published reports". A common source of such self-censorship – and the one governing my choices within this study – derives from the need to protect the participants.

Thus, in the present study, when faced by material strikingly sensitive in nature and/or highly capable of bringing embarrassment or harm should the participants be identified, I simply did not give the information (not even in an invented form). The inclusion of such information into description and publication could, after all, have served to upset the participants, to attract unwanted publicity, and/or to permit others to treat the participants in an exploitative or hurtful manner (Lee 1993: 191). On the advice of Lee (1993: 191), I did however guard against a too "sentimental" approach. So, while I persistently tried to be as aware as possible of all potential consequences of description and publication, I consciously remained wary of exaggerating any of these.

Dissemination

Obviously, besides publishing this study in the form of a thesis I also foresaw, as part of my responsibility as a researcher, that the results of this study would be disseminated to a wider audience (cf. Lee 1993: 194-195). This expectation was sparked by my sincere longing to grant the lived experiences of ME sufferers a truly wide coverage. Thereby I hoped to inspire a better understanding of them and their illness. Such popular understanding could also possibly catch the attention of potential users, policy-makers, and even members of the elite who yield significant power. In addition, a broad coverage of this study – as of any scientific study – could only work towards a wider understanding of the doings and workings of social research among the very public that supports and very often (has to) take part in it.

A guiding frame of reference

In the production and publication of my description of the social reality under study, I was firmly guided by the ethical principles of my discipline. For me, the general thrust of these principles is summarised in the principle of "beneficence" as identified by Kvale (1996: 116). This principle demands that the risk of harm to a participant should always be minimal. In addition, the sum of potential benefits to a participant and the importance of the knowledge gained should always outweigh the risk of harm to the participant. My adherence to this principle was substantially enriched by my personal sense of integrity and ethical intuition.

My concern throughout was not only with the specific individuals involved but also with the larger collective of which they were a part. My responsibility as a researcher did, after all, encompass the duty to anticipate and be aware of both the immediate and the delayed consequences of my choices and actions for those both directly and potentially involved (cf. Lee 1993: 192-193; Kvale 1996: 116).

Thus, in description and publication, I relied on both the explicit rules of my discipline and the more personal and tacit intuitions of my Self to guide me. All in all my genuine concern was for all those who were involved.

Conclusion

When I constructed a description I longed to go beyond the obvious and thereby to create a different reality. This was certainly not intended to be "the" reality. Instead, it was rather

more like a story, one that would represent the product of a dynamic, interactive research process. To allow others to fully appreciate this story, I needed to reconstruct the journey I had followed in its construction. I dedicated Part V to such a reconstruction.

During the process of construction I remained acutely aware of my responsibility to protect the participants and the community they represented. Hence, I very consciously employed disguise and self-censorship with the explicit goal not to distort, but to protect. In this process, I was steadily directed by the ethical principles prescribed by my discipline as well as by my own sense of honesty, justice and respect for all those involved.

Throughout I was dedicated to producing a description – a story of understanding – that would not only be truly faithful to the experiences of the participants, but would also, in terms of both its significance and its implications, reach beyond the immediate…

Questions of credibility

The credibility of a qualitative research study is customarily determined at the hand of its validity, reliability and objectivity (Smaling 1998: 9-23). However, these terms have recently been marked by a substantial measure of controversy, contention and dispute. In fact, Rubin and Rubin (1995: 85) strongly contend that these terms are not at all appropriate within the domain of qualitative research. Indeed, these authors feel that, "trying to apply these indicators to qualitative work distracts more than it clarifies". Consequently, I will henceforth consider a somewhat different approach to evaluating the credibility of this study; an approach based on *transparency*.

What many discussions concerning the credibility of research do have in common (Rubin & Rubin 1995: 85-87; Smaling 1998: 18-22), is a clear-cut emphasis on transparency. In other words, where a study's credibility is at issue, it is often advised that this quality can be best exposed by rendering the research process in its totality as transparent as possible.

For Rubin and Rubin (1995: 85-87) as well as Smaling (1998: 19-22), such a rendering transparent should encompass a comprehensive recording of literally the entire research process. This record should, then, include thorough descriptions of all methodological, theoretical and personal aspects of the research process, its progress, its context and its

participants. In addition, it is also deemed important to incorporate an explicit consideration of the rationale and reasoning underlying the choices made and arguments presented throughout the study.

Rubin and Rubin (1995: 85-87) and Smaling (1998: 22) contend that such a high level of transparency renders the research process open to independent scrutiny both within and beyond the research community. Through such scrutiny the credibility of the study can be fairly assessed.

Aside from enabling such an assessment of credibility, transparency in the research and its presentation carries the promise of still further benefits. Indeed, according to Rubin and Rubin (1995: 85-87), the demand for transparency encourages the researcher to remain close to the data both during the research process as well as in the presentation thereof. This, in turn, enhances the researcher's ability not only to show convincing evidential support for the conclusions of the study, but also to show how these conclusions may, in terms of their significance, reach beyond the directly studied research setting. So, through a thoroughly transparent account of the research, the researcher can reveal how the conclusions of a study, in part or as a whole, may be informative, helpful or usable beyond the immediate context (cf. Kvale 1996: 233; Smaling 1998: 19).

Lastly, Kvale (1996: 234-235) suggests that to render a study transparent is to envisage possibility. In other words, while "telling it like it is", a researcher can also "tell it like it can become". A researcher can present and examine alternatives of thought and action and so explore a novel way of knowing and doing. In the process, the researcher may challenge and transform the conventional and, thereby, indeed enrich the science itself. All of this (and perhaps still more), becomes possible simply by exposing a study and its contents to scrutiny; by truly rendering it transparent.

Thus, a transparent description of a study, such as this one, will not only reveal its credibility, but will also profoundly enhance it in terms of its conclusions, its significance, and its implications.

Conclusion

I have transcribed, analysed and interpreted the data. My personal contribution to this process is evident throughout. It was *my* choice how to transcribe and present the data, how to develop a novel way of assembling it anew, and how to present a final interpretation through a description of the social world under study.

Ideally, the sum of my choices would result in products with claims to knowledge so powerful and convincing in their own right that they would carry their own validation with them. For this to happen the research procedures would be clear, the results evident, and the conclusions of the study intrinsically convincing as "true". Appeals to external certification or official stamps of approval would then become secondary. Such research would indeed make questions of credibility superfluous.

However, we cannot assume that research procedures, procedures and results are intrinsically evident and clear. Instead, they have to be made so. Hence, to establish whether all questions of credibility can indeed be made superfluous in my study, I need to describe it in lucid and transparent terms. This conclusion again echoes and supports the epistemological approach, and specifically the freeing of knowledge through the practice of critical reflection adopted in Part II.

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Summary

Throughout the design of this study I was guided by the firm regulatory principle of doing justice to the social world being studied. I wanted it to speak, its voice(s) to be heard. Like Dey (1993: 53-54), I found that this vision caused my methodological approach to evolve more as a journey up a mountain than simply walking down a straight path.

At the onset of this journey up the mountain I had determined to regard the social world that I wanted to study as a unique, dynamic reality inhabited by active, creative human beings. In order not to loose sight of this distinctly human world, I every so often stopped and turned to look at the horizon. At these times I saw the surrounding countryside as it emerged through the perspective afforded by my new position. While it was the climb that had made this view possible, I was of course only able to obtain a different perspective if I remembered to look as well as to climb.

By looking, I could attain a fresh view, not just of the surrounding countryside, but also of the path I had taken. As I looked down at the path I had already treaded, parts of my journey became too faint to discern, others became clearer. The patterns and beacons that emerged were important because I knew that I would later have to map this journey for others - as I had indeed already started to do. This does not mean that I regard my journey as directly repeatable in any significant sense. Such a view would, after all, require of me to believe that the world I chose to look at was a stable, static one – and this I could not do. I was not interested in a static entity devoid of life itself. My focus was on a vibrantly dynamic human world. Thus, far from rendering my research journey repeatable, I simply noted the path I had taken so that, when telling others about it, they would be able to trace my steps and appreciate what I had seen.

When I stopped to look at the countryside and the path I had already travelled, I also peeked ahead. By taking a closer look and adjusting my direction I could seek out the most appropriate trail. Admittedly I had a fair amount of freedom in mapping out the path to follow. Still, my every footstep was determined by my intent to do justice to the social world I had longed to view. Hence, it was imperative that my chosen path would not be insensitive to the undeniably human nature of this world, that my footfall would indeed reflect my respect for this world on which my entire journey depended.

Some parts of this journey towards the ever-alluring summit were easy, swift and straightforward, others were difficult and required considerable care and effort. Along the way I took some devious paths, certainly not always going straight or even going up the mountain. Occasionally I even had to retrace my steps. This climb, with its circuitous paths, tangents and apparent reversals captures the dynamic and non-sequential character of my research journey. Inevitably, the twist-and-turn character of this journey at times rendered the progress of my climb painfully slow and tedious. Yet, I nevertheless remained steadily directed towards the view at the top. What is more, my progress was throughout (and especially at the end of the climb) rewarded by unique vistas which made it possible to reach a novel understanding of the humanness that marked the world below my gaze.

While I cannot describe in Part 111 every intricacy of my climb to the top of the mountain, more will be revealed in subsequent chapters. It is in these chapters that the translation of my journey into the minutiae of actual interpersonal, interactive human relationships will be explored. It is also in the chapters to come that the panoramic view afforded by this journey will be revealed. Perhaps there is nothing remarkably radical about this journey and the view it offered. But I believe that, if it is presented well, this path towards understanding is sufficient to offer and inspire care, caution and even change. What is more, it will do justice to the human world I had set my gaze upon.

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PART IV

Introduction

There is a multitude
Of Demons –
Tiny though they be –
Tying knots
In Jubilation
Inside of me.

- Betty Sue Fox, a ME sufferer of more than 20 years (1999: 29)

In these few words Betty Sue Fox succeeded in giving expression to the experience of a severe illness shared by so many others. But what exactly is the nature of these demons who so maliciously cause havoc in the life of Betty Sue and other ME sufferers? What is involved in the subjective illness experience of ME sufferers? Part IV is dedicated to the discoveries I made in my pursuit of an adequate answer to this question.

My quest for a greater understanding of the chronic illness experience of ME sufferers, of the demons at work inside them, is fundamentally based on an acceptance of Cassell's (1991: 35) contention that suffering is ultimately a personal matter. It is, hence, the sufferer who enjoys primary insight into the presence and extent of such suffering.

Consequently, the discoveries presented in this Section are primarily based upon the personal experiences of the four ME sufferers who participated in this study. I will not claim that these four "cases" are "representative" in any statistical sense. But I do contend that they symbolise, portray, and represent something important about the experience of illness. They offer powerful, if idiosyncratic, illustrations of the very essence of the severe chronic illness experience.

The participants' accounts of their illness experience revealed that the dimensions of chronic illness extend to virtually all levels of human existence, from the molecular to the social. Each level where life is lived is marked by intense complexity. Each level is a chapter in the story of their illness experience.

To make sense and reach an understanding of the complexity involved in each ME sufferer's story, I will commence with a glimpse into the physical severity and disability which results from ME. Although the physical reality of this disease is not the primary focus of this study, it is certainly not in any sense separable from the social nature and consequences of illness and suffering.

Leading ME researcher, Dr. Jay Goldstein (1990: 17) describes ME as "a psychoneuroimmunologic disorder meaning it has elements of psychological, neurological and immunological dysfunction". In other words, ME affects the patient's thinking and emotions, the brain itself, and the body's immune system. The ME sufferer is therefore likely to experience the physical and mental impact of ME as encompassing virtually every aspect of his or her functioning.

The experience of the participants in this study substantiates this observation. They experienced the very real and immediate impact of ME most severely in a number of key areas. The participants noted the severe fatigue and fatigability that accompanies ME. For them, fatigue was not a normal recovery state following exertion. Recovery is exactly what did not happen. Instead, intense fatigue and weakness persisted. The participants also suffered from severe pain syndromes, at times penetrating their entire physical being. In addition, participants experienced crippling cognitive dysfunction. They were no longer able to take for granted the ability to read, learn or recall. They forgot words, names, even people. This experience was augmented by the auditory and visual dysfunction that accompanied their illness. Such dysfunction seriously impeded the sufferer's ability to fully enjoy and participate in life. Lastly, the participants commonly refer to disturbances in their sleep patterns. For most of them the onset of the illness was marked by severe hypersomnia, while more erratic sleep patterns marked the later stage of the illness.

Thus, from fatigue to sleep... these are just some of the most prominent symptoms experienced by the participants in this study. That this list is far from all-inclusive is evident from the wide array of additional signs and symptoms mentioned by the participants. For instance, these included chemical imbalances in the brain, seizures, vertigo, frightening brain storms, anxiety attacks, emotional lability, a constant high temperature, increased sensitivity to heat and sunlight, skin irritations, marked weight gain and bloating, clumsiness, endometriosis, incontinence, even dental problems. Truly, an almost endless list which sharply highlights the

severe and confusing pattern of signs and symptoms that distinguish the physical reality of ME.

Thus, for the participants the very real, immediate and forceful impact of ME was revealed through the pervasive onset of a wide array of harshly severe symptoms. Yet, in addition to coping with sleeping too much (or too little), with feeling exhausted and weak, and with struggling to communicate or be communicated to, the participants also had to deal with the utter unpredictability and variability of the signs and symptoms that marked their chronic illness experience. That is, while participants did not know which symptoms to expect, they had discovered that whatever symptoms appeared would persist – and would turn what was previously possible for them into the impossible. In fact, a sense of not being able to do, of utter incapacity, at times became a way of life. Sadly, genuine disability became part and parcel of all the participants' experience of the physical reality of ME.

Yet, the all-encompassing and fiercely intrusive physical reality of ME is but one side of the coin. As Natalie despairingly expressed:

Ek wens dit was net *'n fisiese siekte – dit sal* alles *soveel makliker gemaak het…*

On the other side of the coin lies the human reality of ME. The distinction I draw here between the physical and the human reality of ME corresponds with the distinction made in the philosophy of medicine between the terms "disease" and " illness".

Within the latter context, according to Jennings' (1986: 865-866), "disease" refers to demonstratable patho-physiology or patho-chemistry and is diagnosed by the demonstration of pathologic features through investigation of relevant symptoms and signs. A pathological diagnosis is, therefore, a statement about a patient's body based on evidence that is independent of the patient's reports or actions, and so is final. Disease, as such, with its focus on the objective indications of a specific impaired state, corresponds with the physical reality of ME as described above.

Whereas "disease" is a matter of physics and chemistry whose presence is betrayed by physical signs, "illness" is an experience the presence of which is often communicated by complaint. Its study ultimately depends directly on phenomenologic analysis of experienced suffering as expressed through individual self-reports and behaviour (Jennings 1986: 866). "Illness", in other words, refers to all the experiential aspects of bodily disorder as shaped by

those factors governing the perception, the labelling, and the explanation of the discomforting experience (Fitzpatrick 1989: 259). It is a subjective state of suffering. Hence, as Lloyd et al. (2000: 472) rightly remark, it "can only be understood and defined with reference to the sick individual". This conception of illness corresponds with the human reality of ME which clearly transcends the merely biological and physical consequences of organic malfunction. The human reality involves the person as a whole – physically, psychological, emotionally and socially.

But why is the human reality important? Why does it deserve any attention?

According to Wessely et al. (1998: 404), its importance is twofold. Firstly, "because without it one cannot hope to comprehend the extraordinary passions and disputes that accompany the condition, and which, while not unique to ME, are certainly more prominent there than elsewhere". Secondly, "because the very uncertainty of ME provides a window into modern ideas of illness, which would not be open in illnesses with a more defined pathophysiological basis".

Moreover, a greater understanding of the human reality of ME is important simply because the participants say so. The centre stage position of the human reality within the experience of ME is indeed supported by compelling statements such as:

... die menslike aspek van die siekte word 'n geweldige *probleem self, dit word 'n tweede probleem van die siekte... en dit moet definitief aangespreek word op 'n manier. (Natalie);*

and:

... d..die sosiale aspek en die psigiese aspek raak amper *groter as die siekte self.* Definitief! *(Natalie);*

and:

... die fisiese komponent daarvan is... is moeilik om te hanteer elke dag, maar ek dink wat baie mense... afskeep is... almal konsentreer so op die fisiese deel daarvan dat jy die emosionele en die geestelike deel daarvan heeltemal afskeep... En op 'n stadium haal dit jou in... (Denise);

and yet again:

Coping with the emotional aspects of ME... was probably the most difficult task for me (Helen).

For Natalie and the other participants their experience of ME did not so much concern the very nature of the disease itself, but was rather more closely bound to the reaction their illness provoked both in others and in themselves.

Thus, to develop a better understanding of the human reality of ME, of the subjective illness experience, I will, as Cassell (1991: 52) recommends, focus on two distinct aspects of the human condition: firstly, the interaction of the person with the social world, and secondly, the complex personhood of the sufferer.

A focus on the ME sufferer's interaction with the social world will build upon the conviction that "there is no self without others" (Cassell 1991: 40). Indeed there is, as Cassell (1991: 40) asserts, "no consciousness without a consciousness of others, no speaker without a hearer, no act or object or thought that does not somehow encompass others. There is no behaviour that is not, was not, or will not be involved with others, even if only in memory or reverie". Accordingly, there is almost no limit to the ways in which the ill person's experience of suffering may be influenced by the social world where life is lived.

I will therefore devote considerable attention to the influence of those social forces which shape the subjective experience of ME. Such a substantial focus on the social side of the ME experience does not in any way imply that ME is fundamentally a social construction. ME does however exists in the real world, where people such as my participants experience real suffering. In this world, sufferers encounter wide-ranging attitudes toward illness and toward ME in particular. Understanding these interactions and the difficulties that often result is not an intriguing footnote to the experience of ME. It is as much part of the condition as any putative neurobiological, psychological or virological process which may be involved in the physical reality of the disease.

The examination of the social identity of suffering will be followed by a consideration of the personhood of the sufferer. A person has a relationship with the Self. A person has a set of roles, obligations, rights, and responsibilities. A person also has a body and thus has physical and mental abilities and actions. A person has a past, a present, and a future. A person has a life of the spirit, of dreams, of fantasies and of secrets. These dimensions of personhood not only exert an influence on but are equally influenced by the experience of illness and suffering (cf. Cassell 1991: 38-43). Hence, to gain greater insight into the human reality of ME, the complexity of personhood will be thoroughly probed.

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Chapter 11
Medical encounters and confrontations

In my pursuit of a greater understanding of the chronic illness experience of ME I paid considerable attention to the very first source of aid approached by those who feel ill: the medical profession. Members of this profession make a crucial contribution to sufferers' attempts to meaningfully reconstruct their world around a chronic and severely disabling illness (cf. Field 1976: 347).

Modern medical practice is, however, marked by a striking paradox. It is indeed, as Jennings (1986: 865) recognises, "a hybrid, a mixture of art and science", for "in addition to addressing problems specific to the investigation and treatment of physical diseases, it necessarily addresses those diseases in living persons. Consequently it is confronted by patients' personal experience of their disease... as distinct from the disease process itself".

This distinction between disease and the subjective experience of that disease often translates into separate nuclei of attention: whereas patients are primarily concerned with their experience of illness and suffering, physicians appear to concentrate their expert attention on the disease itself. The discussion below will show that for the ME sufferer this disparity often gives rise to a profound sense of confusion, disappointment and sheer desperation.

Nurturing wellness

For the ME sufferers in this study the road to wellness was firstly directed at obtaining a diagnosis, thereafter they sought adequate medical care.

When considering the process of diagnosis, Field (1976: 357) writes that "once a person has been tentatively identified as ill by himself or others, he may seek out a physician in order to obtain a diagnosis of what is wrong with him, for diagnosis is seen as the first step to recovery".

Before considering how participants took this "first step", it is important to understand the importance of the diagnosis which is eventually received. Firstly, a diagnosis explains. A

diagnosis is, as Field (1976: 357) emphasises, "of crucial importance to how the person views his illness". Violon (1982: 31) similarly states that a sick person "needs to have a name and an explanation for what he feels... He needs it for himself in order to be able to comprehend what is going on in him". Sick persons need a diagnosis in order to understand and make sense of their own suffering. Secondly, a diagnosis objectifies. Field (1986: 355) and Ware (1992: 353) contend that the attachment of a diagnostic label often serves to resolve or, at the least, to mitigate the anxiety, uncertainty and ambiguity which accompanies the onset of a severe illness such as ME, by objectifying the situation. Thirdly, a diagnosis legitimates. A diagnosis is often regarded as the physician's "stamp of approval" that the person is genuinely ill. Field (1976: 337) suggests that this "stamp of approval" serves to "legitimate the status of the sick person as ill". The sick person can no longer be viewed as somehow morally suspect – as a malinger or hypochondriac – for he or she has received a medically endorsed label as being ill. Fourthly, a diagnosis structures. According to Field (1976: 355), the diagnostic label serves to structure the situation by pointing towards the expected treatment and prognosis. This in turn directs the attention of the ill person as well as those with whom he or she interacts towards the appropriate attitudes to be adopted and actions to be taken regarding the illness.

In this study I encountered two contrasting experiences of the process of diagnosis, of how participants experienced the "first step".

The first is typified by Denise's account:

Mmm... die dokter... het half... het half tot ons redding gekom deur die feit dat hy ME erken en diagnoseer en... en... mmm... dit het... dit het 'n groot verskil gemaak... as jy besef wat... wat aan die gang is, hoekom is... hoekom... hoekom voel jy moeg, hoekom is jou lyf seer, hoekom... kan jy nie konsentreer nie, hoekom dit, hoekom dat, dan... dan maak dit dit net soveel makliker... Sy diagnose was 'n verligting... uiteindelik het iemand besef 'alles is nie net in jou kop nie'.

The participants found not knowing incredibly difficult to bear. The failure of the medical profession to name their condition left participants feeling not only betrayed but also with no means of coping. Without a diagnosis there was no way to fight the illness, no way to make important life decisions - there was only a sense of paralysis. Hence Denise's relief when the medical practitioner finally recognised and diagnosed her condition as ME. For Denise, the diagnosis offered a sufficient explanation of her condition. In helping her to make sense of the syndrome of signs and symptoms which she experienced, it relieved (at least in part) the confusion and anxiety she had experienced while *not* knowing what was wrong with her body. It objectified her situation for her. It legitimated her status as being genuinely ill and removed

any suspicion of psychological illness. Even though the diagnosis could not offer any guarantee in terms of treatment or prognosis, merely having her condition diagnosed as ME made the situation subjectively easier to bear.

The second, contrasting, position is exemplified in Natalie's recollection of how she was first diagnosed:

... hy het toe nou gesê hy vermoed nou maar dat ek ly aan CFIDS, wat natuurlik iets heeltemal vreemds is, ek bedoel, op daai stadium, jy weet, niemand weet daarvan nie... mmm... jy weet, dis... dis vir jou net iets in die donkerte... En ek bedoel, ek was nie eintlik enigsins... die diagnose het vir my eintlik maar niks beteken nie, want dit sê mos nou maar eintlik niks, daar is nie eers baie inligting omtrent... daaroor nie...

The diagnosis left Natalie in the dark, no closer to understanding her condition than before she was diagnosed. It did not offer any explanation. It did not bring any objectivity to the personal turmoil and confusion that the onset of ME had evoked. It had no power to legitimate her position as being severely ill. It did not offer any hope of treatment and perhaps of a positive prognosis. The ME diagnosis brought her no certainty or clarity. It had no power to affect her subjective experience of the illness favourably.

While it is difficult to identify the exact rationale underlying the difference between these two contrasting experiences, it is reasonable to argue that the level of knowledge about ME at the time of diagnosis played a significant role.

Denise was diagnosed in the mid-1990s. At that stage ME had already become part of public knowledge, especially in the deceptive identity of "yuppie flu". In other words, Denise had had the opportunity to read about it in the media or to hear about it from others. She had some knowledge prior to the diagnosis about an illness known as "yuppie flu" or ME. Hence, the diagnosis to her was not such a foreign entity. It even made sense to her. Natalie, on the other hand, was diagnosed in the late 1980's during a time when very little was known about ME. Very few people had heard or read about ME, let alone actually known someone who had it. For Natalie a diagnosis of ME was completely devoid of any power to bring help or relief. For her the absence of any prior knowledge of the illness transformed the diagnosis into an empty, meaningless phrase. It brought no power to explain for there was no shared knowledge of the illness in her immediate environment. And without meaningful terms to describe it, it was difficult to argue convincingly for ME as a disease in a social setting. For Natalie, then, the diagnosis for ME was not a "real" diagnosis at all.

Thus, it was the lack of sufficient knowledge about ME, and not the nature of ME itself, which carried the potential to bluntly destroy, for some, the power of diagnosis to explain, objectify, legitimate and structure the illness experience.

Now, armed with a diagnosis for their illness, however poorly understood, participants continued on the road to wellness and sought adequate medical care for their condition.

According to the participants' experiences the "adequate medical care" they did receive was characterised by an open recognition of the restricted nature of medical knowledge, a sensitive understanding, an unfaltering commitment, and a holistic approach to the patient as a whole person.

Firstly, the importance of an open recognition of the restricted nature of current medical knowledge was clearly reflected in participants' accounts. Helen, for instance, says:

I admired these doctors who were willing to admit their own confusion and lack of answers...

Cheryl also recalled:

... we preferred to go to him, because although he... he honestly... said that he didn't know anything about ME, he was very willing to listen and help us symptomatically a bit...

A similar sentiment was detected in Natalie's account:

Hulle was baie eerlik omtrent die feit dat daar nog nie 'n kuur is nie, hulle het aan my nooit enige beloftes gemaak nie en het probeer help met simptomatiese behandeling... ek... is baie-baie dankbaar vir die goeie hulp wat ek wel van sommige ontvang het.

These accounts show that the limited nature of current medical knowledge need not preclude the delivery of adequate medical care. Indeed, as Lloyd et al. (2000: 472) state, "people with ME are clearly ill, and are often disabled, even though an underlying disease process has not yet been identified. Our goal as medical practitioners is not only to identify and treat disease, but also to help relieve suffering and disability, whatever the cause". Thus, while doctors should be prepared to recognise the limitations of their current state of knowledge, this should not prevent them from responding adequately to their often distressed and confused ME patients (Oldmeadow 2000: 76-77).

Secondly, the participants emphasised the importance of an open expression of understanding and acceptance of their suffering by the doctors they consult. Cheryl, for instance, related her positive encounters with a doctor who exemplified sensitive understanding:

... this chap... mmm... knew everything that was at that stage to be known about ME... he was... well, it was... a tremendous... comfort to us to find a doctor who was relating... who was a... mmm... he could almost describe me to me, if you know what I mean... He could relate to everything I was saying... and nothing I said to him was un... unusual, he'd seen it all before, he could put all the symptoms under the umbrella of ME... I was very grateful to him... and he tried to help me... for about a year and a half we saw him regularly and he treated me symptomatically... So... this guy was an enormous help to me... for almost two years this man gave me hope that what I had was real, recognisable and that the symptoms could be controlled to a certain extent.

For Cheryl, and the other participants, those doctors who offered genuine understanding and empathy promoted an experience of adequate medical care even where definite answers were lacking. The importance of such an approach is supported by authors such as Kriel (1997: 186), Lloyd (2000: 472) and Oldmeadow (2000: 77) who encourage medical practitioners to adopt an empathic and non-judgemental style, to acknowledge what their ME patients are feeling, and to display acceptance of their patients' suffering. For the participants this sensitive style of engagement among doctors rendered their journey toward wellness all the more tolerable.

Thirdly, a sensitive understanding of the ME sufferer's situation should be complemented by an unfaltering commitment to nurture the patient all the way on the road to wellness. Denise related a particularly vivid expression of such care:

Sy was... sy't ook baie gehelp, sy't... as dit nodig was dat sy in die nag moes uitkom, dan het sy in die nag uitgekom en sulke dinge, wat 'n mens baie waardeer, want jy... jy kan nie net in jou kar klim en dokter toe gaan nie... Mmm... en so, sy het drips en goed by die huis kom doen, wat 'n groot... verligting was dat jy nie elke keer hoef hospitaal toe te gaan nie en... Mmm... sy het baie gehelp om die medikasie en goed goedkoper te kry... wat ook 'n groot verskil maak, want die medikasie het omtrent... word nogal 'n astronomiese bedrag... So, sy het baie gehelp... by haar het ek 'n ander faset van dokter wees... half ervaar... sy... sy stap saam met jou die tweede myl...

Also, Natalie's experience showed that even when faced by uncertainty and confusion a medical practitioner could still provide committed medical care:

En toe omtrent die derde k... derde keer wat ek by die psigiater instap... en ek onthou... ek het by die deur ingestap by hom en hy't vir hulle gesê... iets lyk nie vir hom reg nie... toe het ek al begin sukkel om te loop... En hy't dadelik vir hulle gesê hy gaan my hospitaliseer en hy glo eintlik glad nie in sy eie dia...diagnose meer nie... Wat ek die Here voor dank, want as ek nou nog langer moes sukkel met... met... mmm... met die idee van ek het sielkundige probleme en ek... en ek gaan net voort en voort en

dwing my liggaam... En toe het hy my nou... jy weet, toe het hy nou maar begin rondkrap en soek en... hy't rêrig nie geweet nie... En... elke keer as ek by hom kom sal hy vir my sê, nee, jy het nie simptome vir depressie nie en ek kan jou nie behandel nie, maar ons kyk nou maar net verder wat kan ek vir jou doen... En... die... die psigiater wat ek gehad het is die beste wat ek voor kon wens, want hy het my nie een oomblik verkwalik of enigiets nie...

For Denise and Natalie, their medical practitioners' willingness to demonstrate a commitment to continued care served to guide them along the path to wellness, providing hope and the expectation of improvement throughout. Lloyd et al. (2000: 472) as well as Oldmeadow (2000: 76-77) stress that the management of patients with ME demands of medical practitioners a commitment to constant, continued care. For participants, such medical care fostered an invaluable sense of "stability in the uncertain world of sickness" (Cassell 1991: 78).

Lastly, in the provision of adequate medical care, the medical practitioner's honesty, understanding, and commitment should ultimately find expression within a holistic approach to the patient as a whole person. However, for most of the participants, encounters with such a holistic approach were largely confined to their contact with alternative or complimentary medicine. Note Denise's experience in this regard:

Wat die komplimentêre gesondheid betref... ek vind oor die algemeen daardie mense meer simpatiek en meer... meer met 'n holistiese benadering... en hulle het ook oor die algemeen meer tyd... Dit is nie soos 'n dokter waar jy 'n kwartier in en uit is en jy met 'n papier in jou hand na die apteek toe gaan nie... Mmm... in my... in my si... in die verloop van my siekte het die komplementêre mense my *meer* gehelp as die ortodokse mediese professie...

Denise's account reveals that a holistic approach required both time and an effort to listen to the patient actively and attentively. It is only then that attempts to address physical symptoms can be meaningfully complimented by sound advice on how to cope with ME on all levels. To loose sight of the person as a whole would be to negate any possibility of providing adequate medical care for the ME sufferer. Indeed, Imhotep (195?: 2-3) clearly states that "no doctor can treat disease; he can only treat the person who has the disease – with his full and free co-operation". In fact, 'the necessity of the personal approach... is always present... You are the sufferer, you are the one the doctor must get to know; and he must get to know not only the sound of your lungs, the beats of your heart, the feel of your tummy – but the state of your mind. He must assess not only how your body reacts to disease, not only how your mind reacts, but your whole body-mind, your psycho-somatic system, *you* – the person in the body". It is the person as a whole, the complete interaction between bodily perception, emotion and

cognition, that will affect the course of the illness, the effectiveness of the treatment, and the rate and even the extent of recovery. As Denise's account shows, the necessity of such an explicitly holistic approach is even more pronounced in the management of a chronic and severe illness like ME where the body can never be regarded as a separate world merely functioning in parallel to the remainder of the person (cf. Field 1976: 355-356; Kriel 1997: 186-187; Violon 1982: 32).

Once their condition was diagnosed, the participants equated "adequate medical care" with an honest recognition of medical limitations, an empathic understanding and acceptance of their experience of illness, a commitment to continued care, and an unreserved appraisal of the wholeness of the sick person. According to Kriel (1997: 186) and Lloyd et al. (2000: 472), such an approach to medical care continuously builds toward an effective therapeutic alliance between doctor and patient; an alliance that holds the promise of progress on the road to wellness.

Cruel encounters

Participants related these experiences:

Dokters is onkundig. (Natalie)

... there is an overall gross lack of understanding of ME within the medical profession. Most of my encounters were frustrating and dissatisfying... (Helen)

Dit was 'n frustrasie om... om hier te soek en daar te soek en nêrens rêrig 'n antwoord te kry nie... (Denise)

Unfortunately, the horrid message conveyed through these quotes represents the majority of participants' cruel encounters with the medical profession: doctors do not understand ME and generally do not know how to treat patients who suffer from it.

Why? What is the origin of this ignorance? Why so many cruel encounters in the doctor's surgery? Why does it involve ME and those afflicted by it?

I argue that the ignorance within the medical profession, and hence, the cruel and disappointing encounters recalled by all the participants, is born in the biomedical model as the underlying philosophy within which modern medicine operates.

How physicians approach their patients and the problems they present is very much influenced by the conceptual models into which their knowledge and experience are organised. Commonly, however, physicians are largely unaware of the power that such models exert on their thinking and behaviour. This is because the dominant models are not necessarily made explicit. Rather, they become that part of the fabric of education which is taken for granted, the cultural background against which they learn to become physicians. Their teachers, their mentors, the texts they use, the practices they are encouraged to follow, even the medical institutions and administrative organisations in which they work, all reflect prevailing conceptual models of the era of modern medicine. It is this implicit and subconscious philosophy that gives their way of doing things "an aura of naturalness, of having-to-be-that-way, of God-given normality", and that "prevents them from questioning those very assumptions". This dominant philosophical model can be referred to as the biomedical model (Kriel 1989: 324).

Engel (1977: 130) explains that, in modern Western society, "the dominant model of disease today is biomedical" with, as its name suggests, molecular biology as its basic scientific discipline. "It assumes disease to be fully accounted for by deviations from the norm of measurable biological (somatic) variables. It leaves no room within its framework for the social, psychological, and behavioral dimensions of illness. The biomedical model not only requires that disease be dealt with as an entity independent of social behavior, it also demands that behavioral aberrations be explained on the basis of disordered somatic (biochemical or neurophysiological) processes". This model is, as Kriel (1989: 324; 1997: 182) recognises, clearly based on a mechanistic view of life. According to this view, man's body is assumed to be a machine that can be *understood completely* in terms of the arrangement and functioning of its parts – with no reference to other social dimensions and phenomena related to health. This means that in true biomedical fashion, the diagnostic process is to abstract the patient from his or her concrete existence and to assume that the patient, who is conceptualised purely as a biological organism, can be diagnosed in a context-free environment (Kriel 1997: 184). Because of this combination of pure reductionism and Cartesian dualism, only physical-chemical data are seen as having any meaning – and as having "ultimate explanatory power" (Kriel 1989: 324). Since its inception in eighteen-century Europe, this approach to medicine

has been portrayed as objective, technical and scientific (meaning non-social), and has provided the ultimate foundation for the scientific study of disease as a *strictly* biological entity.

The biomedical model dictates the medical profession's understanding of the concepts of health and illness, which renders these concepts everything but self-evident. Within this framework health is understood as "faultless mechanical functioning of the body machine" – once again excluding all other phenomena that could be related to health (Kriel 1989: 324). Similarly, disease has come to exemplify "a category of natural phenomena urgently demanding explanation" (Engel 1977: 130). Disease is regarded as "a person-centred, harmful, and undesirable deviation or discontinuity... associated with impairment or discomfort" (Fabrega in Engel 1977: 130). In other words, disease becomes a purely biological phenomenon that reflects the malfunctioning of bodily mechanisms (Kriel 1997: 182). And, because "the condition is not desired it gives rise to a need for corrective actions. The latter involve beliefs and explanations about disease as well as rules of conduct to rationalize treatment actions. These constitute socially adaptive devices to resolve, for the individual as well as for the society in which the sick person lives, the crises and uncertainties surrounding disease" (Engel 1977: 130). For modern Western society, these beliefs, explanations and rules of conduct find reason and structure within the framework provided by the biomedical model.

Thus, in modern Western society, the biomedical model represents the fundamental basis for the scientific study of disease as well as for the dominant culturally specific perspective about such disease. It is a perspective that strongly "embraces both reductionism, the philosophic view that complex phenomena are ultimately derived from a single primary principle, and mind-body dualism, the doctrine that separates the mental from the somatic" (Engel 1977: 130).

While a model based on both reductionism and dualism may offer a powerful tool for understanding disease, it also has the potential to create profound misunderstanding when applied unwisely. For starters, its definition of disease as a deviation from the biological norm implies a particular conception of "norm" or "normality". Yet, as Findlay (1993: 121) shows, "normality" is not a standard judgement. It is a concept open to different interpretations. It invites questions on how it was determined, who determined it, and where its application might cease to be relevant. For Findlay, these underlying aspects indicate that the definition

applied here is not a purely objective measurement in the sense of being neutral and value-free as is assumed in the biomedical model. They also point to the risk that the definition might be wrongfully applied, subjecting patients to contextually inappropriate judgements about their physical condition. Furthermore, the biomedical model may, as Lloyd et al. (2000: 471) and Engel (1977: 134) point out, be particularly harmful when, because of its almost exclusive reliance upon diagnostic tests, recognised pathophysiology, and established pharmacological and other physical treatments, it (purposefully) neglects the impact of non-biological circumstances upon biologic processes. In fact, the biomedical model entirely neglects the psychological, social, spiritual and environmental aspects of illness (Kriel 1989: 324). In turn this may lead to immense frustration among "those who find what they believe to be their legitimate health needs inadequately met by too technologically oriented physicians" (Engel 1977: 135). Thus, the conceptualisation of disease within the biomedical model is not only likely to differ from the patient's actual experience of the illness, but may in fact aggravate it.

In this study it is shown that the participants' experience of their illness was unmistakably shaped by the pervasive influence of the biomedical model upon many of the medical practitioners they consulted. To demonstrate the manifestation as well as the consequences of this influence, I will consider two accounts that are not only particularly illustrative but also completely representative of the bulk of each participant's contact with the medical profession.

Natalie:

... ek dink nou spesifiek aan 'n dokter... ek het na die dokter toe gegaan telke male... ek was vir baie toetse en... hulle het niks verkeerd gevind nie... en toe het hy nou maar gesê hy is nou maar seker ek is depressief. En ek kan so goed onthou hoe ek vir hom gesê het, maar ek... ek is seker daarvan ek *is nie*, ek mag miskien so voel as gevolg van die feit dat ek so sukkel, maar ek is... ek voel baie siek. En ek... ek onthou hoe hy nou sy laai oopgemaak het en hierdie pakkie kaarte uitgehaal het met al die simptome van depressie en hoe hy hulle so uitgepak het en... dit so voor my neergesit het en hoe meer ek vir hom sê, maar, ek is *oortuig* daarvan daar is iets verkeerd met my, hoe *harder* het hy daai kaartjie neergesit op die tafel, jy weet... om vir my te probeer oorreed dat ek het al daai simptome.

Cheryl had this to say:

I met an anaesthetist I didn't know. I... I asked to see him... When I came to be pushed down to surgery... I said, 'I actually don't want to go into surgery without knowing my anaesthetist'... So, we get down to theatre... and I... I still haven't met the anaesthetist. I'm going to lie there, *at his mercy*... So, they pushed me into a side room and called him. And I sat up in the bed and I prepared to... do my humble, polite... routine... and lower my eyes and... and look as though I was worthless in the sight of the great doctor story. ...(sigh), golly, (sigh)... he just waded in boots and all and said, 'Gmhf, you're the one that wanted to see me before the operation. *I* do *not* like *your* attitude.' I said, 'what... *what* attitude?

I haven't even told you why I wanted to see you here'. He said, 'I can tell *everything* I need to know as you... as you get into theatre and you're lying there, I hook up my instruments and I know what I need to know'... So, I said to him, 'well, actually, that's *really not* good enough *for me*, because I've had some bad experiences with... with... anaesthetics'. And he said, 'Augh, if you must, tell me about them!'. So, I tried to give him a brief sketch of how... 'I honestly don't want you to think that I expect you to believe ME exists, but there *are* doctors who've diagnosed me with a muscular condition, which *sounds* like what one reads about ME. *However*, be that as it may, it would appear that I have these weird reactions to a..anaesthetics that I never had *before*... I had ME. I mean, it is *completely* different...'. But he took *absolutely* no notice *at all* of what I told him... I wasn't making a fuss, because I thought I was going in for open-heart surgery. I was... I was simply wanting the anaesthetist to know my reactions to anaesthetic. But he totally misunderstood me, you know, he thought I was neurotic.

These two accounts tell of cruel encounters with the medical profession and offer a clear display of both the influence and consequences of the biomedical model. Natalie and Cheryl's experiences clearly highlight medical practitioners' reliance on test results, their diminished capacity to listen to their patients, their propensity to assign what is not found in the body to a state of the mind, their arrogance in openly questioning patients' personal awareness of their being, and their profound inability to comprehend an illness that is both as complex and as subtle as ME. These attributes point to the array of consequences that follow when ME is encountered within the clinical medical practice where the biomedical model is still dominant. There are three principal consequences which I will now consider more closely.

The first significant outcome which results when the biomedical model is applied to the ME scenario may be described as the "cookbook method" (Goldstein 1990: xi). Goldstein (1990: xi) says, "my own feeling is that many doctors stop thinking once they get their diplomas. Once they are out in practice, there is such an overwhelming amount of information pouring down on them and there is so much to learn, that they tend to do things by what I call the 'cookbook' method. If it's not in the cookbook (which is the sum of their acquired knowledge), then it simply doesn't exist. This approach reveals an underlying assumption that presupposes medical knowledge to be sufficiently comprehensive to recognise all (real) disorders presented by patients (Fischer-Rosenthal 1992: 140). As a result, we have doctors telling patients that they really aren't sick or that their symptoms are all in their minds. Can you imagine telling someone who has swollen lymph nodes, fevers and other obvious symptoms that these are all imaginary?" Unfortunately, many ME sufferers like Natalie and Cheryl can imagine such a scenario – they were there and they actually experienced it at first hand.

Expanding on the "cookbook" method, Goldstein (1990: 2) says that "you come in with symptoms and they look in the cookbook (of their medical minds) to see where your symptoms fit. If your illness happens to fit a recipe in their cookbook, they give you a diagnosis and prescribe a treatment. However, if you happen to be so unfortunate as to have an illness that is so new (to medicine) that it's not in the cookbook, they are lost as to what to do. Too often their response is NOT to see this as a challenge and say, 'Now here's something unusual that will take some thought and research'. Instead they too often turn a blind eye to the illness and deny that it exists. 'But,' you the patient protest, 'I'm sick!' 'You can't be,' this type of doctor replies (in his mind). 'Your symptoms simply aren't in my cookbook, ergo, either you're lying or you've got a mental problem. Since I wouldn't want to insult you by saying that you're lying, I'm going to refer you to a good psychiatrist.'" Does this sound familiar? Goldstein's description of the "cookbook method" indeed bears an uncanny similarity to the typical experience of the participants in this study.

Thus, the biomedical model does not inspire doctors to listen to their patients because they rely almost exclusively on test results. Because ME has yet to be reliably associated with any identifiably organic pathology, a barrage of tests for diagnostic purposes are ordered. When these tests, rather predictably, deliver negative results all around (because they were designed for other illnesses) it leaves the doctor at a loss. If nothing shows up in the tests, no disease can be accurately recognised. Hence, as there are no "numbers to be fixed" no treatment can ensue. In frustration, the doctor then promptly refers patients such as Natalie or Cheryl either to a specialist or to a psychiatrist (Ware 1992: 351). The patient who dares to suffer from a poorly defined disorder is doomed, with no single diagnostic test and no simple treatment options available. This approach reflects a deep-seated biomedical mode of thought: the assumption that what counts as "scientifically real" (and hence worthy of further investigation) must be physically measurable (Kriel 1997: 183). Hence, if it does not show up in the test results and therefore has not been observed and so cannot be measured, it does not exist. Or more specifically, if it does not show up in the test results, it does not exist in the body. What is not in the body must then be in the mind.

One could hardly ask for a clearer illustration of the mind-body duality at work in medical practice. Cassell (1991: 34) contends that, in accordance with the mind-body dichotomy, the body has been exclusively assigned to medicine. As a medical category, the body has no room for the concept of person. Hence, the person has found a place in the category of mind. Where the mind is problematic (i.e., not identifiable in objective terms), its very reality

diminishes for science, and so too does that of person. The concept of person then becomes associated with the subjective, with that which is not truly "real" and which therefore falls outside the domain of scientific medicine.

This dichotomy between the body and the mind, the real and not real, extends to the patient-doctor relationship. There the doctor, as the one who deals with the body (which is seen as "real"), is given the role of the "expert", the one knowledgeable about the (passive) patient or, more specifically, the patient's body. In turn the patient is confined to that space which is reserved for the stories about the personal meaning of living with the syndrome – but not to that space which is provided for expert explanations. The patient is assigned a passive role, where any indication of knowledge of his or her own condition and treatment would immediately be in conflict with the practitioner's position. In other words, the mind-body dichotomy transpires within the roles that emerge in the doctor's office. Here each social role is believed, or is made to be believed, to possess unique and exclusive forms of knowledge. The "expert" knows about the syndrome and its treatment. The person living with ME knows about personal suffering. Even though these roles or categories rarely correspond with the multiple experiences of the people who suffer from ME, those who dare speak "out of character" are often silenced. These silencing effects are directly the result of the impenetrable boundaries which cordon off the knowledge in "medical science" into an unquestionable domain. Thus, the medical practitioner is the expert on the body and the "real", the patient the merely passive recipient of medical treatment (cf. Heaphy 1998: 24-25).

Running concurrently to this construction of the doctor-patient relationship is what Kriel (1997: 183) identifies as the particular nature and implications of the doctor's agenda. Kriel describes this agenda as one aimed at diagnosing the physical disease causing the patient's symptoms. The doctor is therefore not interested in the patient's needs, fears and expectations (in other words, in the patient's agenda), but rather wishes through direct questioning to draw the patient into the reductive, mechanical and materialistic medical agenda – all in order to make a diagnosis and prescribe treatment (Kriel 1997: 183 & 186). The biomedical paradigm which in this way dictates the structure of the interaction between the patient and the doctor is further likely to inspire a sense of separation or even alienation. As a result of this particular configuration of the patient-doctor relationship, biomedicine has become "separate" from the individual patient. The uniqueness of *this* patient, in *this* situation, interacting with *this* doctor has been submerged in general categories which are largely impersonal. Biomedicine is

therefore easily viewed as standing "outside" the individual and even as representing a contrasting view in the attempt to solve health care problems (Kaufman 1988: 339).

According to Cassell (1991: 104-108) this mind-body duality has furthermore led to a belief among physicians that diseases are the "real" things – the things that count – and that symptoms are the direct, unmediated manifestations of such diseases. That is, disease is tacitly "conceived of as a *thing* per se in the world", as a material entity – and typically as "a malfunction" in an (anonymous) human body that can be described in purely physical terms (Kriel 1997: 184-185). This disease is "objective" – it does not bear a personal face nor is it related to any individual biography or life history "(Fischer-Rosenthal 1992: 134). What is more, a patient is assumed to be capable of clearly "representing" a disease – this malfunction – by means of his or her bodily symptoms which will, in turn, become "the objectives of the physicians' gaze and manipulations" (Fischer-Roenthal 1992: 140). Within this context, the task of the physician is clearly confined to purely that of correlating the clinical findings (as "represented" by the patient) with a classification of physical diseases – that is, "to diagnose a disease rather than to understand a patient" (Kriel 1997: 182).

Cassell (1991: 105) strongly questions the validity of the belief in diseases as "real" things. He firstly contests the assumption that diseases are real. He argues that "diseases are not real things in the manner they are conceived to be. Diseases are real in the same sense that ideas are real, concepts are real, and categories are real... Diseases do not have *independent* existence; they are not things like lungs or livers. Cancer of the breast does not have free-standing concrete existence and neither does pneumococcal pneumonia. Diseases are abstractions, conceptual entities that serve a concrete purpose. They are generalizations, categories that contain the facts about the abstraction in the sum total of its numerous expressions. Only the individual expression of the disturbance has actual touch-them-with-your-hands existence. But even though they exist, the expressions of the disease can never be observed by themselves, because while they have existence, they do not have independent existence" (Cassell 1991: 105). Disease is, therefore, not in any sense an entity that enjoys independent existence in concrete reality.

Cassell (1991: 108) goes on to contest the view that symptoms are the unmediated expression of diseases. He argues that "the bodily occurrences that lead to the process of perception and then verbal expression of symptoms are inevitably subjected to interpretation and distortion by the patient. The effect of the addition of the patients' personal meanings ineluctably

individualizes and personalizes the altered physiology that is the disease process, so that what emerges and is presented to the physician is the unique illness unfolding over time that is the expression of the disease in a particular person" (Cassell 1991: 108). Thus, patients are not capable of somehow directly "representing" their experience of physical disorder to the physician. Neither are physicians capable of perceiving the experience of the patient as an independent observer who simply recognises an already classified pattern of disorder. This raises some doubt about the physician's quest "to pull the disease free, so to speak, from the obstructions and entanglements of the patient... It turns out that the object of the physician's search, the disease entity, does not exist in concrete reality but is merely an abstraction without independent existence. The only thing the clinician can work on (a paradox for medical science) is *this* sick person" (Cassell 1991: 108). It is in fact, as Fischer-Rosenthal (1992: 140) recognises, only in interaction with *this* sick person that the physician will be able to develop an understanding of (but not directly perceive) the patient's experiences as they are affected by disease.

While the person – the whole person – represents the primary object of study with which the doctor interacts every day, the biomedical model simply cannot include the patient and his or her attributes as a person, as a total human being. The model "cannot make provision for the person as a whole nor for data of a social or psychological nature, for reductionism on which the model is predicated requires that these must first be reduced to physical-chemical terms before they can have meaning" (Kriel 1989: 325-326). In practical terms this means that the subjective reality of the patient (including his or her world of meaning, hopes, fears, responsibilities and values) is not really part of the disease with which the doctor is concerned. There is in fact a very clear difference between what the doctors understands as disease and what the patient experiences as illness. Based on this, Kriel (1989: 326) concludes that this model renders the very essence of medical practice beyond the reach of medical science. It is indeed as Engel (in Kriel 1989: 326) suggests "an incomplete scientific model" – it cannot deal with the totality of phenomena related to health or disease.

Because disease ultimately finds expression in an individual sick person, Cassell (1991: 32-34) strongly appeals for a rejection of the historical dualism of mind and body. Without such rejection the place of the person in human illness cannot be understood. After all, it is "not possible to treat sickness as something that happens solely to the body without risking damage to the person. An anachronistic division of the human condition into what is medical (having to do with the body) and what is non-medical (the remainder) has given medicine too narrow a

notion of its calling" (Cassell 1991: 34). In the name of adequate medical care, this clearly calls for the (re-)construction of the patient as a whole person.

The second major repercussion of the management of ME in accordance with the biomedical model is the all-too-frequent tendency to pigeon-hole ME patients as suffering from somatoform disorder, and specifically, from depression.

To his dismay, Goldstein (1991: 55-56) finds that ME patients are often labelled as somatocizers. This label suggests that they suffer from a disorder that is marked by recurrent and multiple somatic complaints, of several years duration, for which medical attention has been sought, but that apparently are not due to any physical disorder. Complaints are often presented in a dramatic, vague or exaggerated way or are part of a complicated medical history in which many physical diagnoses have been considered. Nowhere in this description of somatozation disorder are references to be found of recurrent flu-like illnesses or sore throats or painful lymph nodes so characteristic of ME. In fact, as Oldmeadow (2000: 76) recognises, "prior to developing this illness many patients have lived uncomplicated, functional, productive and busy lives, with no hint of psychiatric disturbance or frequent recourse to medical consultations".

ME patients are equally often misdiagnosed as suffering from depression. Goldstein (1990: 57) observes that sufferers, even though they do not meet DSM criteria for depression, may be judged to have "masked depression", a "depressive equivalent", or (to really stretch the point), "depressive disorder not otherwise specified", a catch-all loophole used when a person does not have the grace to neatly fit any other DSM category. This happens despite clear-cut evidence that ME is not a somatic presentation of depression or any other underlying psychological disorder (cf. Hickie et al. 1990; Steyn 1993). Where, then, is the logic in this "it's all in the mind" approach? Perhaps, Goldstein (1990: 6) suggests, it seems easier for many physicians to "explain away" the illness by focusing on the patient's depression than to accept the challenge of dealing with it. On the other hand, perhaps it simply points toward the classic biomedical model in practice: if nothing is wrong in the body, something must be wrong in the mind. Hence, the sick person's own experience of illness can, as in Natalie's account, be bluntly denied.

The impression that ME is a psychological disorder is unfortunately not only prevalent in encounters with medical practitioners like those described by Natalie and Cheryl. It is also

even advanced by researchers such as Barsky and Borus (1999: 910) who define ME as a "functional somatic syndrome", characterised "more by symptoms, suffering, and disability than by disease-specific, demonstrable abnormalities of structure or function". Indeed, they suggest that, "the suffering of these patients is exacerbated by a self-perpetuating, self-validating cycle in which common, endemic, somatic symptoms are incorrectly attributed to serious abnormality, reinforcing the patient's belief that he or she has a serious disease".

In response, English (2000: 329) points out that Barsky and Borus cite no post-mortem examinations, no brain biopsies, no negative findings of any kind. Yet, they say, "evidence suggests organic disease: abnormal findings on single-photon emission compute tomography, positron-emission tomography, and magnetic resonance imaging scans, hypothalamic hypofunction, and cognitive deficits". The burden of proof is on the authors, Barsky and Borus, to show "no demonstrable tissue abnormality". They do not. In fact, they consistently ignored evidence which does suggest an organic cause for ME.

Thus, while Barsky and Borus (1999: 910) state that patients often "devalue and dismiss medical authority and epidemiologic evidence that conflict with their beliefs", the authors themselves seem to have done the same. Their paper ignores, dismisses and distorts research evidence concerning the nature of ME. For instance, when focussing on ME, they often refer to articles which deal with fatigue or chronic fatigue; not with chronic fatigue syndrome. In addition, despite their use of more than 200 references, Barsky and Borus's search of published articles seems to have missed all the studies and reviews which suggest that biological factors play a major role in ME, as well as those studies and reviews challenging the effectiveness of psychological intervention.

English (2000: 329) also argues that even if there were normal histological findings in ME, Barsky and Borus's argument still rests on shaky ground. Schizophrenia was once the quintessential psychiatric illness, reputedly caused by cold, distant mothers. Tissue examination of schizophrenics also revealed no consistent abnormalities. Today, however, schizophrenia is considered a neurological brain disease. Numerous other diseases, including lupus, multiple sclerosis, AIDS, Lyme disease and even cancer, suffered similar fates before "tissue evidence" was available. Albrecht (1999: 18) recalls that, "in the 13th century, for instance, people 'knew' you wouldn't get bubonic plague if you lived a simple, carefree life with many enjoyable but not overly stimulating activities. In the 18th century, gout was regarded as a payback for overindulgence in liquor and luxury foods. In the 19th century

everyone understood that it was emotionally sensitive people – poets, painters, artistic people generally – who got tuberculosis. The 20th century has been no better. When I was in graduate school in the late '50s, we took for granted that asthma was a direct outcome of unresolved Oedipal conflict, and until the '90s everyone I knew accepted the fact that ulcers came from stress and working too hard, being too competitive. Yet, plague, tuberculosis and many ulcers are caused by bacteria; asthma starts with allergy and creates physical alteration of the airways; gout is a metabolic problem. The fact is that no illness affecting a diverse population has ever turned out to be primarily or predominantly mental". Albrecht (1999: 18) terms this tendency among medical practitioners to ascribe any condition that falls beyond the bounds of current medical knowledge to a psychological origin "hysterical medicine". In fact, he somewhat derisively suggests that "hysterical medicine" might even in itself be "an overlooked mental illness" which mysteriously afflicts many physicians as well as some members of the general population.

Angell (1985: 1571) suggests that myths such as those described above surrounding poorly understood disorders appear to arise "when a disease of unknown cause is particularly dreaded. The myth serves as a form of mastery – we can predict where the disease will strike and we can perhaps ward it off by modifying our inner life". Some may consider the belief that a particular mental state is an important factor in the cause or cure of a disease as harmless, even beneficial, since it allows patients some sense of control over their disease. Moreover, it closely corresponds with the Protestant work ethic that motivates patients to participate in therapeutic interventions and to expect that more is better. That is, the more medical intervention sought and received, the closer patients will be (or at least expect to be) to recovery (Kaufman 1988: 346). The belief in the power of a particular mental approach and the Protestant work ethic, taken together, encapsulates one important Western perspective: "that the individual can acquire the ability, through training and perseverance, to reverse disease outcomes and, in fact, to overcome nature" (Kaufman 1988: 346). Unfortunately, this perspective also carries the potential of personal failure. If a patient believed in some method of thought control, yet failed to arrest the progress of the illness, the patient is at fault. After all, "a view that attaches credit to patients for controlling their disease also implies blame for the progression of the disease" (Angell 1985: 1571). A dualistic mode of thought that invokes a narrow "mind-over-body" understanding of illness may amplify into a powerful means of placing the blame on the patient. Hence, while he is not in favour of abolishing all personal responsibility for health, Angell (1985: 1572) firmly states that it is "time to acknowledge that our belief in disease as a direct reflection of mental state is largely folklore".

Goldstein (1990: 54), almost despairingly, observes that each time he dares to believe that the clinical research community has convincingly dismembered, exploded or destroyed the notion that ME is due to some imperfect, even reprehensible, mental state, or to a somatoform disorder, or more specifically to depression, unwary or foolhardy researchers such as Barsky and Borus, or medical practitioners such as those encountered by Natalie and Cheryl, manage to resurrect this destructive superstition. Still, Goldstein (1990: 59) remains hopeful that soon the weight of published evidence should be so overwhelming that those who still choose to make the assertion that ME and depression are one and the same "will charitably be viewed as being in denial of reality".

Thirdly, those who practice medicine in accordance with the framework provided by the biomedical model are simply unable to understand either ME or the sufferer's experience of it.

ME symptoms are vague, as Goldstein (1990: 9) points out, they may wax and wane, and they can be symptomatic of other diseases. In addition, the symptoms do not fall within a single medical discipline but instead cross many boundaries. With no discipline willing to embrace the disease (with the possible exception of psychoneuroimmunology), ME still remains "an unwanted stepchild of medicine" (Goldstein 1990: 87). Furthermore, although the major symptoms of ME suggest a non-localised disturbance of central nervous system function, its pathophysiological basis remains obscure. A diverse array of aetiologies has been proposed, but no simple explanatory model has been consistently supported. Thus, as Lloyd et al. (2000: 472) state, "ME challenges the standard concept of discrete disease categories linked to specific aetiologies. The practitioner is confronted with the challenge of explaining the patient's symptoms without reference to a coherent biomedical model".

In these circumstances, many doctors are reluctant to even admit that ME exists, let alone agree to treat it. If their instruments cannot identify the problem, there cannot be a problem. Many doctors would rather fall back on out-dated notions of "psychosomatic disease" than endorse ME as a real and severely debilitating illness. This is supported by a leading ME researcher, Dr Paul Cheney (in Garloch 1990: 19), who remarks, "the emergence of this disorder has demonstrated a weakness in the medical community's ability to identify and characterize subtle disorders". The dominant model on which the medical community relies, the biomedical model, is simply too simple, too narrow, to explain the nature of an illness such as ME and has, hence, led to serious problems in patient care.

When doctors start believing in instruments and stop listening to their patients, they become unable to understand the experience of illness of the sick persons who consult them. Cassell (1991: 176) explains that in the era of biomedical clinical practice, "the only real knowledge is thought to be scientific knowledge: that which is gleaned from natural science and is objective or measurable. Other kinds of knowing are considered of lesser value". Yet, the question of whether someone is suffering is not open to scientific knowledge. It cannot be verified or empirically demonstrated. It is unavoidably doubtful and uncertain. Consequently, the relief of suffering – as medicine's fundamental purpose – cannot be achieved through purely scientific medicine. This does not imply a rejection of objective facts as the basis of medical science. It simply means that these facts, necessary as they are, are in themselves insufficient to the medical practitioner's task. Suffering is after all the distress of the person as a whole, not of the person merely in the (objective) biological sense. Indeed, "the wholeness or individuality of suffering extends beyond the confines of the body" (Cassell 1991: 211). Cassell (1991: 211) contends that "sick persons, unlike livers or enzymes, do not meet the criteria as objects of science. They cannot ever be completely known or known apart from the knower, and they cannot be measured solely in the objective terms of science... They are ultimately individual and therefore inevitably different from another". Thus, it is clear that focusing only on the body, the biological, represents but a small slice of the total relevant biography of the sick person; relevant, that is, in the provision of adequate medical care.

Very few disorders in modern medicine have generated such uncertainty and controversy as ME. According to Goldstein (1990: 16), Dr. Anthony Komaroff, a well-known and leading ME researcher, is quoted as saying that "even AIDS was simpler than this". Unfortunately, as Goldstein (1990: 2) frankly admits, "the medical profession has badly mishandled the CFS problem". Although there is great reluctance to think that the very way medical science looks at things may be the culprit, it is clear that much of the difficulty surrounds the dominant reductionist and dualist paradigm of biomedicine. The discussion above and, more importantly, the participants' experiences, show that a broader paradigm is called for – a paradigm that will acknowledge the dense web of delicate interconnections between the physical, the psychological and the social which comprise the patient as a whole person. Such a paradigm is likely to advance medical practitioners' insight into the illness experience of ME sufferers and, hence, allow them to provide more constructive roadside support for their patients on their journey to wellness.

In response...

The participants compared the experiences they had with the medical profession to a grinding cycle where hope of relief was regularly replaced by deep disappointment. Denise offered a clear expression of the type of experience which the other participants also encountered:

... en dan ook half die teleurstelling of die... jy gaan... jy hoor van die... 'die dokter' en met 'n verwagting gaan jy na 'die dokter' toe... hopenlik dat hulle vir jou 'n diagnose kan gee en 'n behandeling... en dan werk dit nie... Dan... dis half... jy bou 'n verwagting op en dan is dit 'n teleurstelling... en 'n verwagting en 'n teleurstelling... en dit laat jou dink, maar, jy weet, jy's besig om mal te word... Mmm... so dis weer... die kwessie van jy het 'n verwagting en dit word teleurgestel en jy het 'n verwagting en dit word teleurgestel... Mmm... en dan kom dit maar weer terug op 'moet op prinse nie vertrou nie'...

In this cycle of successive hopefulness and disappointment the latter was often caused by a combination of the very real physical harm following medical treatment, the dire lack of adequate medical care, and the relentless insistence on pursuing the psychological route.

The participants repeatedly cited the physical harm they experienced when submitted to inappropriate medical treatment. Again, it was Denise who offered a hair-raising description of the consequences which followed such treatment:

Dit was vir my... ek het... ek het baie erger gevoel daarna, ek was op baie medikasie en dit gee vir jou konvulsies en newe-effekte en dinge en... Toe ek daar ont... toe ek daar uitkom, toe is ek... ek was omtrent nie in staat om te loop nie, ek was heeltemal... mmm... non compos mentus...

Denise later sadly added:

... ek kan vir jou eerlik sê dat... dat as... as 'n mens half dit... anders hanteer het, dan dink ek sou dit *baie minder* skade gedoen het... dan dink ek is jou pad van herstel vinniger en makliker... Ongelukkig betaal jy net nou nog steeds die prys daarvan... jy weet, skade en goed wat medikasie aangerig het wat jy... wat se effekte jy vir 'n *lang* tyd saam met jou in jou liggaam gaan ronddra...

Cheryl's experience of so-called medical expertise in practice was similarly disturbing:

He (a neurologist)... he too... he put me on medication that... made me feel dreadful... and even more agitated... and... so we went back to the... the doctor... and I said to him I cannot tolerate the medicine... So, I was completely... now this was the first time ever that I became emotional... emotional in front of a doctor... because he put a call through to the neuro... neurologist, while we were sitting there... on the edge of our seats, waiting for help, waiting for an answer, finally got the call through and the GP... said to us the neuro... the neurologist said your reaction to the medication was perfectly normal... far from coming off it, you must double the dose... And I just burst into tears, because I knew that medication was doing me no good at all... I just... I just was so desperate...

Denise and Cheryl experienced that medical treatment did not bring relief. Instead, it simply inflated the burden of their suffering. Suddenly participants' assumptions were overthrown that medicine is omnipotent in its ability to restore normalcy. Naturally disappointment followed for the participants in this study. This is similar to the disenchanting experiences of stroke sufferers in Kaufman's (1988: 346) study when medical treatment failed to deliver any physical results.

Experiences of medical treatment which are physically harmful were often alternated by experiences where no treatment was offered at all. The patient was pricked, poked, palpated, submitted to a variety of technical examinations, to innocuous or painful diagnostic means, and to varied therapeutics, all to no avail. Even where the ME diagnosis was finally accepted, it held no guarantee of sufficient medical treatment, as Natalie's experience revealed:

'n Ander dokter het telke male wat ek hom besoek het my nie eens deeglik ondersoek nie. Hy het net vasgestaar teen die diagnose van ME, hy het gesê jy weet wat jou diagnose is, jy weet dit is ongeneeslik. Sy belangstelling in simptomatiese behandeling, al was daar ernstige simptome op daardie stadium, was minimaal.

Also consider Cheryl's statement:

We are losing them as a 'caring profession' in many, many cases... Even the old family doctor has all but disappeared. In my opinion good old fashioned physical examinations, thoroughly done, knowledge of the patient's home situation and lots of listening would be far better than all these tests in MANY cases.

When the sufferer experiences neither understanding nor receives treatment, desperation sets in. It therefore came as no surprise when Denise despairingly disclosed:

'n Mens bereik 'n punt waar jy jou eie dokter wil wees...

Thus, during the sufferer's interminable journey through the medical mill, a grave sense of disappointment followed each of the repeated instances where they were confronted by the utter inability to provide adequate medical care. They eventually experienced the lack of recognition of their illness, and the apparent absence of any intent to at least treat its symptoms, as a "betrayal" by the medical profession (Ware 1992: 351).

According to the experiences described by the participants, this sense of disappointment was further augmented by medical practitioners' insistence that they follow the psychological route. The absence of observable evidence of pathology, together with the ambiguous status of the illness in professional medicine, combines to preclude the possibility of a physical

diagnosis. And if an illness is not physical, it must, it follows, be mental. Natalie, for instance, recalled:

... ek dink aan 'n dokter waar ek was... wat my vir 'n... *twee en 'n kwart jaar* behandel het en... vir my gesê het op die ou end... mmm... sy kan my nie gesond maak nie, so sy is oortuig daarvan ek het iets anders, iets psigies, verkeerd met my. Ek onthou daai dag so goed, want... ek het *so hard* probeer en *alles* wat sy gesê het het ek so goed gedoen, jy weet, *elke reëltjie* nagekom... ek het *nooit oortree* of iets nie... en ek was *so ontsteld*, ek was *so hartseer*... dat dit vir die *soveelste* keer gebeur het...

This experience shows that when faced by a patient who presents unaccountable and seemingly untreatable aches and pains, the medical practitioner may, as Violon (1982: 30) acknowledges, indeed be tempted to treat the patient as "a malinger, as mentally disturbed or as an hysteric". That this represents a very strong possibility is confirmed by Green et al's (1999: 67) finding that more than three quarters of the ME sufferers who had participated in their study had been exposed to psychological labelling. In response, the patient will inevitably be reluctant to follow the psychological route: "the 'real' doctors do not believe him, don't want to treat him anymore, think that he exaggerates his pain, and consider him as crazy" (Violon 1982: 31). Patients feel that talking about their past, childhood, parents, family, or feelings make no sense. They think that they are receiving an inappropriate response to the question of their physical suffering because they are convinced that their psychic life has nothing to do with their suffering. Patients know that their suffering is not "imaginary". Consequently, as the participants' accounts revealed, they experienced disappointment in the medical profession's inability to accept and understand the patient's illness experience.

Thus, when exposed to physical harm, to utterly inadequate medical care, and to outright demands to pursue psychological help, the grinding cycle again and again ended in disappointment. For this participants this dreadful outcome caused two processes which operated concurrently: the first, a changing awareness of Self, the second, an increasing disenchantment with the medical profession.

Natalie firmly placed the influence of the medical profession's response to ME within the context of the sufferer's awareness of Self when she states:

... mense se konsep van die siekte... kom direk terug na jou toe.

And more specifically:

... die dokters speel 'n... 'n vreeslike groot rol... by 'n mens se... se self-indrukke...

Hence, how medical practitioners responded to the experience of illness of ME sufferers influenced their perception of Self. Indeed, sufferers were liable to feel misunderstood, blamed, labelled, even stigmatised. Consider Helen's account:

At a time when I was desperately trying to understand my own illness and acknowledge the changes it brought with it, I had a great need to be understood. I did not expect immediate answers as to the cause, effect and prognosis with regard to ME, but I needed the doctors I consulted to accept my symptoms as real and as affecting my life in a very overwhelming way... Their frustration was overt and contributed greatly to the uneasiness I came to feel whenever I consulted a new doctor. The majority of times I came away feeling misunderstood and labelled as one suffering from a 'psychosomatic illness'...

Ware's (1992: 350) research suggests that labelling the patient's illness as psychosomatic – as "all in her head" – embodies a particularly severe delegitimizing experience for ME sufferers. Worse yet, for the ME sufferer like Helen, the medical profession's inability to recognise, comprehend and treat ME not only delegitimises her own experience, but also adds the additional burden of stigma. In this respect, Green et al. (1999: 64) suggest that "it is likely that ambiguous, chronic disorders... create a vulnerability to stigmatization by others in people with the syndrome". Furthermore, "because medical professionals in our society are accorded high status... they may be an important source of stigma in patients with chronic, etiology-defying illnesses". Green et al's (1999: 64) concern is that the experience of stigma, as an additional stressor, "could interfere with the process of recovery from CFS or, at the least, impact adversely on the quality of life of people who already suffer". This possibility is supported by Totman's (1990: 157) review of numerous research initiatives which converges on one common finding: "that an individual's physical and mental health is profoundly affected by other people" – obviously including high-status medical practitioners.

The potential of the seemingly high-minded medical professional not only to cause a dreaded stigmatisation, but also to pervert the sufferer's illness experience, was strongly supported by Natalie's description:

... die mediese professie... sjoe, ek kan nou *eerlikwaar* sê dit het my selfbeeld baie aangetas. Dit *moes nie*, maar dit *het*, want ek het... 'n mens het s... 'n sekere soort respek vir iemand wat... iets weet, wat jy dink iets weet, jy sien... En dit maak ongelooflik *seer* as jy by 'n dokter kom, nadat jy... *uiteindelik* miskien vir *jouself* uitgeklaar het dat jy nou nie... mmm... besig is om jou verstand te verloor nie en jy weet daar is fisiese goed verkeerd en jy is nou *oortuig* daarvan en jy kom sê maar by 'n *paar* dokters en *almal* van hulle oortuig jou maar weer andersins... en sê vir jou, nee, maar, wag, ons sien *niks* verkeerd nie... En dit is vreeslik moeilik, want daar begin dit... dit is miskien waar die groot *geveg* binne-in my begin het... die elke dag se bevraagtekening... 'n mens begin jouself ontleed en bevraagteken en wonder... is *hulle* nie maar reg nie, *hulle* kry dan niks nie... En hulle... *eintlik*, hulle... is miskien nie bewus daarvan nie... maar werk hulle vreeslik met jou kop, want... hulle smokkel daarmee, want... wat

hulle van oortuig is, probeer hulle jou van oortuig en dit is nie noodwendig *reg* nie en jy dink omdat dit die mediesie professie is... *is dit*.

Natalie's account shows the self-doubt which is induced by the ignorance of the medical profession. It also shows how such ignorance undermines the validity of the perception and understanding which ME sufferers have of their illness. This theme was also identified in Green et al.'s (1999: 70-71) study of ME sufferers. They found that "among our subjects, physicians' apparent ignorance of, or sceptical attitude toward CFS, played a role in the potential damaging 'delegitimation of illness experience': physicians reconstructed reality to signify that the illness of the CFS patient was 'not real'". This apparent assault on sufferers' sense of reality of the nature of their illness results in self-doubt.

Ware's (1992: 352) study of ME sufferers similarly confirms that the experience of having their perception of reality repeatedly denied quickly paves the way to self-doubt. She observes that "those who had had such experiences described in frustrated tones how at one point or another they felt compelled to accept the possibility that what they were feeling might, after all, be 'all in their heads' and that that might mean they were 'crazy'". Ware is of the opinion that the fear that their illness may after all be psychosomatic confronts self-doubters not only with the possibility that they do perhaps suffer from a psychological disorder, but also with the stigma which this entails. The suffering of self-doubt thus "lies in the prospect of adding the burden of a stigmatised identity to that of living with a chronic illness that is severely debilitating, basically untreatable, and of questionable authenticity in the eyes of others" (Ware 1992: 352). This means that the consistent denial of their experience by the medical profession leads ME sufferers, like the participants in my study, to disbelieve their own experiences. And this – along with the stigma such a question of personal reality might invoke – adds directly to their suffering.

When the reality of their illness experience was questioned, this inevitably led the participants to doubt themselves. For them, the mere fact that the validity of their experiences was questioned hinted at the possibility that their very characters were suspect. In other words, whereas an illness acquired through external agency such as a viral infection is seen as blameless, an emphasis on psychological factors being the cause of their illness is perceived as pointing to personal failure or weakness of character. This predicament is eloquently expressed by Ware (in Wessely et al. 1998: 271): "Mind is the seat of reason and volition, body the locus of 'natural' biological processes that lie largely outside the realms of rationality agency and intention. The task and the challenge of mind is to exercise dominance over the

body, to bring it under rational control. With control and volition come responsibility. We are held accountable for what we command or intend. Thus paradoxically, sickness of mind ('loss of reason') signifies not only failure of will and loss of control, but a failure of will and loss of control *we brought on ourselves*. It follows that we are responsible; psychological disorder is 'our own fault'". Thus, despite "the fact that psychosomatic medicine was originally conceivable as an antidote to biological reductionism", as "an attempt to bring mind and body together in biomedicine in more or less equal union", experiences shows that "psychosomatic diagnoses have come to be classed with psychiatric disorders", thereby "reproducing dualistic thinking and sharing the stigmatized status of mental illness as a disability we 'bring on ourselves'" (Ware 1992: 356).

Like Natalie, all the participants in this study experienced this dilemma. Whenever the medical practitioner unthinkingly assumes the role of "expert", which is made possible by the biomedical model, the ME sufferer's awareness of her own body, of her own physical reality, was often denied and rendered suspect. At one time or another each participant has been either directly told or made to feel that her illness was trivial, that it could be dismissed as psychosomatic, or that it could only be the result of her own doing. The blame, humiliation and even shame that this approach evoked – because it made the sufferer feel wrong about her own interpretation of reality – was one of the most devastating experiences caused by delegitimation. As a result, each participant has at one time or another doubted her own experience of reality. At times some even believed this to be true, but thankfully not permanently.

All the participants' changing awareness of Self eventually developed into a stronger belief in their own experience and their own reality, to such a degree that even when they were faced again by an ignorant and disbelieving practitioner, their own perception of reality now remained secure. Note, for instance, Natalie's account:

... ek het hierdie... absolute *duidelike*... prentjies wat ek kan herroep in my kop waar ek by dokters gesit het wat... vir my goed gesê het wat ek op daai oomblik *geweet* het is *so* verkeerd, so onwaar, want ek *het* nou al myself so *baie* keer ontleed en ek is *so seker*...

Natalie's view of herself as knowledgeable of her own physical state clearly opposed the practitioner's account of her condition. But Natalie's belief in her own experience remained steadfast. She knew she was truly ill and no longer required the practitioner's affirmation that this was so.

Cheryl expressed an even stronger personal perception of reality:

... it would be very easy to become frustrated at the fact that it is not acknowledged by... a doctor here, but that... that I don't actually *need*, because I... I... I'm... I believe in myself enough to know that I... if I think... if I... what I'm experiencing is *so* obviously *real* and it's been reinforced so many times that it's not just mental or emotional or anything like... And it... every time it *is* reinforced it's an encouragement to me, because that... remains important to me that I don't... mmm... sink into a... a... syndrome of... of *thinking* I'm ill and perhaps *not* getting up when actually that day I *could* get up, for example. So, it's very important to me to co..constantly reassure myself that it is a physical illness, but it happens in ways that I don't even look for... and which are sometimes unpleasant, because the physical symptoms can be so overwhelming. But... mmm... no, I don't need to be reaffirmed by a medical person... and I don't think I'm ever going to be...

Cheryl's account not only described a new-found confidence in Self and personal reality, but also hints at the second process at work: the growing disenchantment with the medical profession.

Natalie voiced a similar awareness, but more directly:

Heelwat van hierdie negatiewe ervarings het tog maar gesorg dat my respek vir die mediese professie half verlore geraak het. Ek is skepties om dokter toe te gaan, want ek voel... mmm... hulle kan in elk geval nie iets vir my doen nie.

Natalie's description confirms that her repeated encounters of ignorance and disbelief from insensitive medical practitioners led her to lose respect for and belief in the power of medicine, and has even induced a sense of scepticism and alienation. This sensation may lead a sufferer to feel forlorn and disconsolate, especially when desperately ill: if my doctor cannot help me, where should I turn to?

Indeed, after another encounter with medical ignorance, Cheryl said:

So... we again lost a... a... it was sad because... we lost a support structure... it seemed like everywhere support structures were falling down... ;

and after yet another such an encounter:

... once again it... it's like... a carpet being pulled out of u...under our feet... I mean, it's absolutely astounding to me...

Finally, Cheryl was in despair:

I feel I have no doctor. A frightening feeling when very ill.

Cheryl thus experienced a growing sense of disenchantment with the medical profession that was closely accompanied by a stark sense of loss and desolation.

On the other hand, this sense of disenchantment held the potential of an almost empowering experience for the sufferer. Indeed, for the sufferer, it stood to obliterate any sense of intimidation by medical expertise or of embarrassment when seeking help for such a "strange" illness. Thus, whereas a sufferer might have initially felt obliged to listen to "the doctor", even to follow seemingly unhelpful or harmful treatment regimes, repeated encounters with sheer medical ignorance and incompetence, combined with a stronger belief in Self and personal reality, were likely to set the patient free from this obligation (cf. Kotarba 1983: 190-191).

Helen described the insight that guided her towards this liberating experience:

> It took me a long time to realise that I was not necessarily the strange, depressed person I was often being made to feel, but that those who were labelling me as such, were scientifically minded people who were struggling to cope with their own discomfort surrounding an illness that left so many questions unanswered... I found comfort seeing my illness as a new challenge to the medical world...

For Helen, as well as for the other participants, disenchantment with the medical profession did not end with scepticism and alienation. It also brought the wisdom to dismiss an unqualified belief in the medical profession's ability to bring relief and healing. Thus, far from relying solely on the medical profession to bestow confirmation on and bring relief from their symptoms, participants such as Helen were now able to assume the position of 'expert' over their own physical reality. While such accounts should not be excessively exaggerated – or worse yet, romanticised – they do show that there is a different way of coming to grips with this illness. In effect these accounts open up spaces where the voices of other ME sufferers can be heard, and where they can actively engage and, where appropriate, directly challenge the apparently all-authoritative claims of the medical profession (cf. Heaphy 1998: 25).

Thus, the participants' experience of the medical profession's response to ME was marked by a cycle of successive hopefulness and disappointment. In response, participants developed a deeper awareness of Self that grew from self-doubt to self-affirmation. This was accompanied by greater insight into the limited scope of present-day medical knowledge and capacity.

To cope...

The way in which the participants' response to encounters with the medical profession became a process through which they grew and developed, was echoed in the way they eventually learned to cope on the medical front. Their approach speaks of change and of development away from unqualified obedience and trust in medical authority, to self-reliance and a newly clarified image of the ideal doctor.

At the onset of their illness, participants' mode of coping was marked by unqualified obedience to the medical practitioner. Natalie explained:

En ek het... ek het altyd almal se raad baie mooi gevolg... mmm... as jy vir my gesê het... jy gaan nou vir ses maande niks suiker en niks melk en niks stysel inneem nie, sodat daar omtrent niks oorbly om te eet nie, dan sou ek dit doen... ek sou nie een dag verneuk nie, jy weet... dit is nou maar net soos dit is, jy weet...daar is nou maar net geen kans... mmm... want ek wou ook agter die kap van die byl kom, ek kon nie verstaan wat gaan aan in my lewe nie...

Cheryl succinctly expressed a similar mode of coping:

I was still in '94 in the stage where I bel... I had elected to believe and trust the doctors... I presumed the doctors knew what they were doing... then I was relatively passive and went along with most of what the doctors suggested...

It appears as though participants' obedience to whatever the doctor deemed essential followed from their trust in the medical profession. Cassell (1991: 76) suggests that patients' trust in doctors represents their way of solving the intolerable uncertainty which accompanies illness. He explains that when they are ill, patients experience "an increased urgency to act. But, decisions and actions that are seen as having to do with one's very life require levels of certainty that are not available to the sick person – they simply do not have enough information, as no one does in such circumstances. Trust in others is one of the central human solutions to the paralysis of unbearable uncertainty. For these reasons the sick put their trust in doctors" (Cassell 1991: 76). Very importantly, patients indeed have very little choice but to trust the medical practitioner.

Patients' trust in medical practitioners therefore endows the latter with both the power and the responsibility to act on patients' behalf. But what happens when medical practitioners mishandle their power or act irresponsibly? What happens when the patient's interests are not served?

Cheryl offered insight into this predicament as she told of an experience, which was typically experienced by all the participants:

... we've realised some have just been over their heads and not been able to help us... and others have... not really wanted to go the distance with us, because it's looked to complicated... and some of them have been downright unkind...

Cheryl's experience does not testify that her uncertainty was resolved. Neither does it testify of the provision of adequate medical care. It does not testify of doctors acting in accordance with the power and responsibility they are usually expected to exhibit. Instead, Cheryl's account, which represents the experiences of all the participants, testifies of indignant frustration in the face of such dereliction of duty by medical practitioners.

Financially too, the medical profession's failed to handle the ME sufferer's best interests. Consider Natalie's recollection:

Finansieel op lang duur word dit ook natuurlik 'n probleem. Finansieel-gesproke is daar heelwat praktiese probleme. Mediese onkoste vir toetse, dokters, medikasie... dit beloop letterlik duisende rande en dit raak 'n huishouding en almal in die familie se leefwyse. Mediese fondse is gedurig deur uitgeput... Dit is 'n probleem vir my om op die ouderdom... nog op my pa se mediese fonds te bly, al het ek bewyse van 'n chroniese siekte...

Cheryl offers an even more startling account of the financial implications for the person who suffers from ME:

We have... we have had to sell so many things to try to keep up and we're still heavily in debt... It's enormously expensive, because even with the medical aid you're always running out and paying the excess... or the medical aid cover runs out because you're needing so much help from the medical aid... So we've sold our only car, we've sold my engagement ring, all that sort of thing, and... my husband sold his boat... and we still are heavily, heavily in debt... we've made a conscious decision not to sell any furniture so that our house still looks... mmm... presentable, because also, you know, you don't get much for furniture, you get a odd R100 here or there, and what will that help in the end... So we've made a conscious decision to sell everything we can that has any value... and... you know, keep everything else looking fairly normal... So, I mean, no one really knows that I don't have an engagement ring anymore, for example... it's pretty obvious we don't have a car, I mean, that makes life very difficult... This all happened in the last two or three years, that... the money... the money-side of things just totally overtook... by then we just couldn't cope anymore...

Cheryl's startling experience tells of the impoverishment that accompanies chronic illness (cf. Kriel 1997: 186 Ware 1999: 313). In its most benign form, such impoverishment means doing without non-essentials, or sometimes, cutting down on essentials. Like Cheryl and her family, ME sufferers may stop going out for meals, postpone home repairs, sell the second car, and

trade in valuable items for cash. All the while, income (or the ability to generate income) is reduced while expenses relentlessly increase. What makes treatment so expensive?

The answer to these questions lie partly in the process of referral. ME sufferers are typically sent from one specialist to the next – more and more tests, mounting costs – to no avail at all. Again and again the participants pointed out how expensive it was to be on the medical treadmill. Note, for instance, Cheryl's recollection of the second neurologist she was sent to see:

... when every test result, including a R4000 MRI scan did not show results he could 'put in a box' and label he simply handed over a bill for R1800! and left us flat (This did not include the price of any of the tests. We were really battling).

Then came the third neurologist:

He ordered R1000's worth of tests which I did not have the strength to resist or the brainpower to remember that I'd already had some of them (for eg, a CAT SCAN etc) and after two days he simply telephoned my bedside 'phone and told me to stop taking drugs... I went home pretty shattered (to put it mildly) and realized I'd once more lost a support 'system' (network). Also in my unhappy state I did not think to ask the neurologist or the physician for any of my results and my husband simply spent months paying off bills. I wasn't even given the scans, x-rays or anything. (And subsequently too weak & downhearted to demand/request, whatever...)

These are only two of the more than 20 medical specialists Cheryl had consulted during her eleven-year illness. It is not difficult to imagine the costs involved in each of these consultations – the expense, the debt, the problems. What is partly responsible for the high costs is the ever increasing and sometimes inappropriate role that technology plays within the modern medical practice. Reliance on such technology not only "creates a depersonalised and inhuman atmosphere", but, for the participants, also directly contributes to the soaring costs of medical care (Kriel 1989: 327). And here we are only considering the mainstream medical practice. If the sufferer ventures into the terrain of complementary medicine, as many of the participants did, expenses rise even more. Approaches to illness management such as acupuncture, homeopathic remedies, vitamins, nutritional supplements, and non-prescriptive medications are after all only rarely covered by medical aid.

Goldstein (1990: 1) strongly affirms that, in his experience with ME sufferers, too many of them are either misdiagnosed or over-referred to medical specialists. He notes that "it is not uncommon for a patient in these circumstances to ping-pong from doctor to doctor, usually at a cost of tens of thousands of dollars in often inappropriate diagnostic tests all for nothing, since

the patient is not helped by these medical efforts". The patient is not only "not helped", but is also left to bear the added financial burden and the often ensuing impoverishment.

Frustration in the face of medical negligence, combined with grave financial difficulty, did not serve the participants' best interests. Their uncertainty was not resolved and their illness still raged unchecked. Consequently, their trust in the medical profession eroded away, and was often all but destroyed. Cheryl openly admitted:

... then I presumed the doctors knew what they were doing... I now know they don't understand what they're doing... and to a large extent I have to help myself...

Cheryl's profound realisation represents a point which all participants eventually reach. At this juncture, the medical establishment's mismanagement of ME caused the sufferer's unqualified obedience to medical authority to be firmly replaced by two related actions: first the sufferer started to avoid contact with the medical profession, and secondly, the sufferer tended to become more self-reliant.

Natalie clearly expressed the rationale for avoiding contact with the medical profession:

Ek gaan eintlik nie dokter toe nie... ja... gaan ek omtrent nie meer nie, want ek voel... ag, weet jy, dit is net vir my so... *veral* as 'n mens nou na 'n... 'n ander dokter soek, om nou van voor af die hele storie te vertel... dit is al so holrug gery die storie... Gewoonlik lê ek maar nou maar 'n paar dae of... ek hoop maar net dit gaan gou om... So, dit is my oplossing daarvoor... dit is *al* wat ek kan doen.

Cheryl said:

And then... since then we have... we decided... mmm... we'd try and steer clear of doctors as much as we could...

For Natalie and Cheryl, as for the other participants, there was simply no reason to consult yet another doctor. When there was no constructive help forthcoming, there was no reason to return. When it was doubtful that the professional knew more than the sufferer, there was no reason to return (Ware 1992: 351).

When there was no reason to return to the doctor's surgery, the Self became the only hope; hence the development of self-reliance. Cheryl offered a particularly illustrative account of a ME sufferer's ability to find a doctor inside the Self:

My eyesight from the very beginning gave me problems... I did not think of the fact that if ME affects muscles, surely my eye muscles too would be affected – those that control eye movement particularly, I would think... I was taught how to carry on at home, but my eyes became worse and worse...

Eventually... professionals (eye specialists) 'gave up' on me. They simply had no diagnosis for what was wrong. I finally made my own and realized I had to rest my eyes in the same way that I had to rest my body. And I also noticed how easy reading was on 'good' days! It began to fall into place...

At first glance it appears an almost nonsensical expectation to find a doctor inside the Self. After all, most of us are very used to turning up at a doctor's surgery and walking out a few minutes later with a prescription in hand to cure the ailment. ME is not like that: "There is no magic bullet and, at this stage, patients will be foolish to expect one" (Franklin & Sullivan 1989: 163). If sufferers have been used to rely on their doctor for the answers to all their health problems, they will probably have their illusions shattered. Doctors do not have all the answers. As this study shows, this is particularly true in the case of ME.

Herzlich (in Willems 1992: 112) points out that this "new sick person" – the self-carer – "is a new type of personality in our culture". This person is no longer a passive patient, but rather someone who has learnt to respond to symptoms in ways that do bring relief from suffering. In doing so, participants in this study challenged one of the "central distinctions of our society: the often criticized opposition between the knowing who impose their knowledge and those who have no choice but to undergo it" (Herzlich in Willems 1992: 112). Where this opposition no longer applies, the division of knowledge and skills between medical professionals and "lay" patients becomes less and less distinct. The borders have shifted.

Yet, as Willems (1992: 113) recognises, there is still a boundary between the actors in a medical consultation. However porous and shifting this boundary may have become, doctors and patients still remain separated. And patients, like my participants, still find themselves on the side of those who need the expert's knowledge. Thus, despite a firm commitment to avoid medical practitioners and to get along by themselves, participants were still aware of the need for professional help from the medical circle, as Cheryl explained:

... I was feeling worried about... the middle of this year... I realised that for... a year and a half, I've been more or less treating myself... you know, self-medicating, which I didn't feel was sensible... and I was worried... I was really very worried that... I needed a doctor to help me through this.

Thus, while ME sufferers were essentially in charge of themselves, they still needed the help of the medical world to cope with their illness (cf. Cassell 1991: 125). Their search for such help followed many roads. For many participants in this study, as in Ware's (1992: 351) research, seeking help and relief ended in endless encounters with doctor after doctor. Helen described this process of "doctor shopping":

My desperate searching for acceptance of my symptoms and understanding of my illness is evident in the number of doctors I consulted... this could be labelled as 'doctor shopping' but it was a process I needed to work through in coming to accept my illness and the lack of definite answers and solutions it presented to me...

Strauss and Glaser (1975: 32-33) point out that the medical world sees this process of "doctor shopping", of switching and supplementing, or at least only partly adhering to the doctor's regimen, as either an unjustifiable lack of faith in the medical profession or as a search for the impossible cure. However, from the standpoint of ME sufferers, loyalty to one doctor no longer holds the sure promise of relief, let alone a cure. In fact, as Natalie revealed, they very seldom expected a cure:

... kyk, ek verwag nie veel nie... ek verwag nie hulle moet... mmm... ek *wil* nie hê hulle moet my belowe dat hulle my gesond sal maak nie, want ek weet op dié stadium... dat hulle tien teen een sal jok...

In fact, they were rather looking for the relief of suffering, which is after all the medical practitioner's primary task. In the light of the bitterly severe nature of ME, as well as the general lack of medical help and understanding, it was therefore not surprising that participants' quest for relief was often marked by pronounced desperation. They wanted to get better – so much so that they would seek out treatments, even treatments of questionable effectiveness, simply because of their desire to do something.

Consider, for instance, Denise's statement:

Uit desperaatheid het ek onder andere met die volgende in aanraking gekom: homepatie, refleksiologie, aromaterapie, chiropraktisyn, kinisioloog, mikro-nutrient en voedingskliniek, kolonterapie en limfdreinasie.

With reference to an extreme approach that included a lengthy period of strict fasting, Denise said:

En dis... dis weer eens 'n groot paradigma skuif wat jy moet maak... vir so tipe ekstreme behandeling, maar as jy desperaat is dan doen jy dit... Dis 'n plek waar jy by uitkom as jy regtig desperaat is...

Denise repeatedly stressed:

... jy kom op 'n punt wat jy desperaat is en enige iets sal doen...

Cheryl's account reflected a similar experience of desperation:

I *have* investigated dagga... with my chemist, because he has one patient who is on it... by prescription. It is legal... oh, but the ramifications of that prescription... It's *very* difficult to get and it's *enormously* expensive, *enormously expensive*... I mean, I *have* heard people say that it *does* help for... for aches and pains and... there is one or two folk in... in the ME world who believe it might be helpful. But I

wouldn't be able to do anything like that. I would want to do it *legally*... not only because it's *right*, but because... eh... the ramifications of... of taking any substance without back-up should something go wrong... it *absolutely overwhelms* me. No, I... I could never do that. But it's *very* tempting... when the pain is at its worst, you think, gosh, if there was just some way I could get my hands on a powerful substance. Very tempting.

Indeed, in the face of soaring symptoms and medical disinterest, the ME sufferer may, as Lloyd et al. (2000: 472) acknowledge, be dearly tempted to pursue useless or even harmful unproven therapies – including dagga. This is utter desperation.

Thus, in their quest for relief, the participants consulted numerous medical practitioners and, often in desperation, followed countless deviations which offered possible help. Through this process they discovered what they were indeed looking for: the picture of the ideal doctor had emerged.

Firstly, on a very practical level, the ideal doctor should be located in close proximity to the sufferer. Cheryl said:

I could have done with that sort of medical help closer. I could *still* do with it closer. In fact, by tomorrow I could probably do with it...

Natalie supported this wish:

... ek is *nou nog* eintlik op soek na 'n dokter naby...

ME sufferers are unable to travel any substantial distance when they are desperately ill. A journey to a far-away doctor is indeed likely to counteract any possible benefit of the medical treatment. Thus, a doctor close to home is the ideal.

Secondly, the participants' image of the ideal doctor included the crucial ability and willingness to listen attentively to the patient. Natalie highlighted the importance of this:

... al wat ek soek is 'n dokter wat... sal *luister*... dis... dit is so *ongelooflik* belangrik, dat hy net sal hoor wat ek vir hom sê...

Cheryl explains the reasoning behind this strong emphasis on listening:

The difficulty comes in where they won't accept the fact that you've got this... mmm... underlying condition that could be affected by whatever they do. There're certain drugs you can't tolerate and you know jolly well you can't tolerate them, but you haven't got a good enough reason as far as *they're* concerned. You know... and they will override you and prescribe something which you won't even go and... fetch from the chemist, because you know it's a waste of time and money... No doctor likes being

told *anything*. They are *rare*... doctors who are prepared to *listen* in anyway are rare. Doctors who are prepared to have *suggestions* made to them are *rarer still*.

Cheryl provides further substantiation of this when she gave a very clear example of the harm done when the doctor does not listen:

... a physician was called in to give advice... He was yet another 'NO bedside manner' sort and I don't think he ever heard a whole sentence of mine. He chatted on his cellphone, listed tests to the nursing sister and just walked out. We've just discovered he duplicated the surgeon's tests – so two or three days apart we have pathology accounts for exactly the same tests in many cases... If only this man would listen to his patients! I could have told him what tests had been done.

Clearly, much more effective medical care could take place if the medical practitioner would listen to the patient and try to understand the patient's way of experiencing the situation. For the participants this was an indispensable quality of the ideal doctor.

Thirdly, the ideal doctor should have sufficient time available to listen attentively to his or her patients. Natalie strongly emphasised this quality:

En *baie* belangrik is iemand wat tyd het vir jou, want... ongelukkig die medici... my ervaring op die oomblik is hulle is altyd net so *haastig*... En 'n mens... mmm... 'n mens voel skaam om te kla oor klein goedjies, jy weet, maar dit... dit... daar is altyd net so 'n *klomp* klein goedjies... jy weet, en... dan... dan besluit jy maar... jy sal maar oor die helfte sal jy maar niks sê nie, want hulle is altyd so haastig... As 'n mens net rustig kan gaan sit en miskien... mmm... stap vir stap 'n klomp goed kan uitskakel, dan sal dit... dan sal dit ook 'n verbetering wees...

When the patient found that the physician did not have time to listen, it became impossible to forge an effective alliance between the sufferer and the physician in the struggle against ME.

Fourthly, the participants required the ideal doctor to be willing to offer sensitive symptomatic relief. Natalie explained:

As ek vir hom sê... *my* vel aan *my* voete is te sensitief en ek nie kan skoene dra nie, dit is net 'n *klein* probleempie, dat hy *dit* sal probeer na kyk en dink wat kan hy daaraan doen... Die probleem is... die dokters wat ek op dié stadium het, sê vir my die volgende... mmm... jy weet mos nou waaraan jy ly... kyk, hulle glo nou gelukkig, hulle weet nie veel nie, maar hulle weet dat dit bestaan... en dan ontsien hulle *alles*... jy weet waaraan jy ly... miskien is 'n... 'n sensitiewe vel nou maar deel van die siekte-simptome... kom ons vergeet nou maar daarvan, is daar iets anders? Dit... dit is nie vir hulle belangrik dat daar klein goedjies is wat 'n mens kan verbeter, wat ongemaklik is nie...

"There is nothing more I can do" is a devastating statement. It is also generally untrue. Cassell (1991: 125-126) forcibly asserts that "there is virtually always *something* that can be

done to improve the patient's situation, no matter how small or seemingly inconsequential". This neither implies that the ideal doctor should pursue one useless treatment after another nor that the ideal doctor should maintain the pretence that the patient will be cured when this is impossible. Yet, for participants such as Natalie, even the slightest form of symptomatic relief is of importance. It makes a difference to them.

Cheryl's opinion lends further support to this contention:

I think drugs are not... are not... mmm... are not an invention of the devil. I think they *must* be used and they must not... I think doctors must not be so frightened of prescribing, because the intervention that... that gives you a good night's sleep and a time free of pain is not going to be the sort of thing that you are going to seek out to become addicted to... because... well, *I* certainly don't have any drugs that produce any pleasurable sensations, they might bring a *measure* of relief, but that's *all*. So... I... I think there should be more intervention from that side, more to help us through.

Thus, symptomatic assistance and the type of relief sought by Cheryl and the other participants should be directed towards helping them feel in control. When faced by symptoms which flare up, sufferers neither want to feel personally helpless nor surrounded by medical practitioners who appear equally helpless. Instead, they expect their doctors to present them with choices and options that will allow them to still feel personally empowered and in control.

The ideal doctor should therefore be sufficiently knowledgeable about ME to be able to offer such "choices and options". Natalie voiced this need:

... ag, dit sal help ook om iemand te hê wat darem so bietjie van die... van die siekte weet...

Cheryl supported this:

... *I do need their help!* I need their knowledge and I need their intervention.

In fact, Cheryl repeatedly emphasised the necessity of sufficient knowledge ME among competent medical practitioners:

I would *really* appreciate some excellent brains on the subject... you know... I'd really appreciate that back-up... that's the sort of help I would like with the ME... Just somebody who has the sort of... the brains... to help me during a crisis time, you know.

Of course, ME sufferers realised that knowledge of their illness is still limited. However, limited knowledge should not prevent the medical practitioner from at least trying to do something. In other words, the lack of good evidence about the best treatment should not be accompanied by lack of treatment (cf. Cassell 1991: 119; Tuckett 1976: 215).

Lastly, the participants required the ideal doctor to have insight: the physician should be perceptive to the patient's experience of ME. Natalie described this quality as follows:

... so, ek verwag *nie veel nie*, maar ek sukkel om so 'n dokter te kry... en een wat darem *ten minste* weet... dat as ek die dag vir hom gaan sê ek voel nou moedeloos, dat hy nou nie in die lug gaan spring en my dadelik vol anti-depressante wil pomp of so nie, maar dat hy... *met insig* sal dink... dit is *normaal*, dit... dis *verstaanbaar*...

The requirement here was insight into the "full picture" of ME. As Natalie's experience showed the sufferer may, in facing and surmounting the many difficulties of ME, at times feel doubtful, diminished, or deteriorated. It is then the doctor's task to restore ability, to inspire a return to optimism, and to reinforce the capacity to cope with the illness. Such intervention requires a mindful and deliberate awareness of the patient's experience of illness.

In summary: for the participants in this study, the ideal doctor is available close to home, is able to listen attentively, is known to have time for his or her patients, is willing to offer symptomatic relief, is sufficiently knowledgeable about ME to do so, and is perceptive to his or her patient's experience of ME. This image clearly entails a very strong re-focusing on the human skills which a doctor should possess, rather than on the skills involved in purely technical intervention.

In their search for relief of suffering, their ultimate destination, the participants in this study embarked on a process of change and development. Whereas they had initially been more than willing to trust their fate to the "wise doctor", their experience of negligence and financial exploitation eventually all but destroyed their confidence in the medical profession. In avoiding contact with this profession they began to discover the doctor inside themselves. They became more self-reliant; they were in charge of themselves. Their journey towards their ultimate destination did not stop here, though, for they still needed help to cope with their illness on the medical front. They consulted many medical practitioners and ventured along many a side road which promised relief. This journey has helped them to distinguish those qualities which would define the ideal doctor. These are human qualities which testify of a genuine capacity for caring and a genuine desire to help. In their search to cope with their illness the participants are not looking for a miracle or for the impossible cure. They are rather simply looking for relief of suffering, and most of them are still searching.

Conclusion

The experiences of the participants in this study revealed that ME sufferers firstly turn to the medical profession as an important source of aid. In their encounters with members of this profession they primarily pursue relief from suffering. In the medical profession they see a glimmer of hope, a possibility of such relief. Through the trust they place in the profession to afford such relief, they endow their doctors with the power to act on their behalf. Their interests are now in the hands of the knowledgeable doctor.

Yet, repeatedly, participants had to endure the consequences of wholly inadequate medical care. From the preceding discussion it is clear that the provision of adequate medical care is primarily inhibited by many medical practitioners' dominant reliance on the biomedical model. The reductionist and dualist principles embraced within this model prevent medical practitioners from understanding the complexity of ME, from accepting the sufferer's experience and perception of reality, and from acknowledging human suffering as distress which affects the person as a whole. Indeed, within the biomedical model, the doctor's task is to define the disease in biological terms, to determine its cause, and to institute specific treatment. In this world there is no room for the patient's meanings, values, fears and hopes. Those dimensions which make a person whole do not enter the doctor's understanding of health and disease. Inevitably this leads to the depersonalisation of the doctor-patient relationship – and of medical care itself. Furthermore, the tendency to define "medically invisible" bodily complaints as psychogenic and therefore imaginary, is a direct reflection of scientific materialism which accords primacy to substance, equates the real with the physically observable, and discounts or altogether ignores the subjective experience of the patient. Those medical practitioners who operate within the constraints of the biomedical model are restricted from seeing the full picture and, hence, are restricted in their ability to bring relief of suffering. The task of medical practitioners to care for the sick have been artificially circumscribed. This was not done deliberately because no-one is so explicitly directed towards helping the sick than the medical practitioner. It rather points to the intractability of the biomedical model for as long as biomedicine remains efficacious, politically entrenched, and consistent with the core values and concepts of Western cultural tradition, we may expect this situation to continue.

The mountains of ignorance which bar the ME sufferer's way to relief of suffering led the participants to experience intense disappointment and often desperation. They found that the uncertainty of their illness could not be alleviated by the certainty contained in medical knowledge. They discovered that medical knowledge is almost inevitably imperfect. The

emergence of a new "mystery" illness such as ME highlights this imperfection in current medical skills and concepts. The medical profession indeed reveals itself as a profession that is as much searching for answers to the many questions surrounding ME as those who suffer from the illness.

Their encounters with the medical profession led sufferers to come to the conclusion that their illness is seen as not "real" at all, but rather a fabrication based either on their needless exaggeration of everyday complaints (in which case they are malingerers) or on the perception of imaginary symptoms (in which case they are simply "crazy"). In either case, the self-doubt and the threat of stigma induced by the ambiguities of this illness contribute to the suffering of the ME patient. The participants' ensuing disenchantment with the medical profession led them to abandon the unqualified belief they had earlier in the power and ability of this profession to indeed bring relief of suffering. Their trust in the medical profession was cruelly violated. Hence, they often moved to revoke the power endowed on the medical practitioner to act on their behalf. As this power is assumed by the sufferer, a significant change in the balance of power between doctor and patient takes place. Usually within this relationship patients occupy the weaker position. After all, their illness may literally render them powerless and they may be in desperate need of the doctor's help, which makes the patient dependent on the doctor. While the participants in this study are still in need of medical help, they have discovered that their medical practitioners cannot necessarily be trusted to provide such help. Hence, as they are no longer dependent on their practitioners to the same degree as before, they have repossessed the power to exert control over their own body and over their own person as a whole. Through this process the participants fully restored the validity of their own experience of reality. They discovered a new and stronger belief in the Self. They are now in charge of themselves.

What is left for the medical profession to do? Should they simply stand aside? Should they regard their imperfect knowledge as a licence to inaction? Should patients with illnesses falling outside the biomedical model abruptly be left to their own devices?

The participants' experiences point to the contrary: patients require medical practitioners to adopt a more holistic response in which their psychological, behavioural and sociocultural characteristics – along with their physiological and biochemical characteristics – are recognised as influencing the course of their illness (and their recovery), and are therefore directly relevant to medical care (Kriel 1997: 187). In other words patients need to be viewed

in their "wholeness". The participants in this study reject being reduced to biological terms. In this study, then, a holistic approach has come to represent "a more humane medicine" (Kaufman 1988: 339) than traditional biomedicine which so blatantly excludes all but measurable biological variables in the consideration of health problems. The holistic approach furthermore advocates patient responsibility for learning about his or her condition, for making treatment decisions, and for actively participating as a member of the health care team.

In meeting this responsibility, patients like our participants require medical practitioners to guide them actively to discover the doctor inside themselves. In other words, ME sufferers like the participants in this study still need medical help, but of the kind described by the great Doctor Albert Schweitzer (in Franklin & Sullivan 1989: 163-164): "Each patient carries his own doctor inside of him. They come to us not knowing this truth. We are at our best when we give the doctor who resides within each patient a chance to go to work". A call to address the doctor inside another person summons the human inside the doctor. It is this dimension of doctor-hood that will acknowledge the human person in the suffering and will respond humanely to the suffering person. For ME sufferers this is the road to wellness – to the relief of suffering, the fundamental calling of medicine.

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Chapter 12

Family: In fine style?

In accordance with the human reality of ME, the illness experience of the ME sufferer is not confined to one person. Instead, it involves many diverse contexts of human interaction. In this study, it became evident that the sufferer's family represents the first of these contexts where the influence of ME is intensely perceptible. As Natalie observed:

... dit is definitief so dat dit ander mense om my dadelik raak... en my huismense *veral*...

Indeed, for Natalie and the other participants, the family most often represents the main context where life is lived – a context which is not only greatly influenced by their illness experience, but which in turn exerts a powerful influence on their illness experience. Consequently, in order to achieve a greater understanding of the illness experience of these ME sufferers, of their human reality, a thorough investigation into the intricate family relations in which they were engaged must be made (cf. Strauss & Glaser 1975: 67).

Nurturing wellness

Numerous authors, such as Collinge (1993: 99-101) and Totman (1990: 143-154), extol the extraordinary benefits that follow from "good quality social support" for the sick person within the family. These authors clearly see that such support intends to nurture the sick person along the road to wellness.

While wellness is indisputably the ultimate destination, one cannot but wonder: what qualifies as "good quality" family support for the ME sufferer?

Helen provided an answer to this question when she succinctly described her experience of the essence of family support:

Without my family and the support they offered, my struggle with ME would have been far harder to bear. My family offered me endless understanding, support and advice throughout my illness. They were never too busy to stop and listen... or to go out of their way to do the odd chore for me. During the times when I felt most alone and isolated, I knew I could always turn to them for some warmth and encouragement... My family encouraged me to trust myself when those around me had almost convinced me that I was 'strange' or that the most likely diagnosis was depression...

It is clear that the question "What is a supportive relationship?" will elicit as many different answers as there are different people. Still, Helen's account identifies a number of crucial elements of support that are strongly echoed in each of the other participant's experiences.

Firstly, Helen emphasised that an important element of "good support" is the unconditional belief in the reality of the illness and the experience of illness. Franklin and Sullivan (1989: 103) offer substantiation of this when they say that the most important means of support open to family members is simply "to believe in their illness".

The importance of such an unconditional belief in and acceptance of the ill person was endorsed by all the other participants. This was underscored by the intense sentiment in Cheryl's words:

My nuclear and extended family do not necessarily understand ME, but believe me *completely*... mmm... I can say that my side of the family, nuclear, both sisters, Dad and his brother... and his... sister all accept me completely... It all helps. I am completely accepted as I am... it's wonderful... because they are *completely* and *utterly* understanding, believe that I am ill, they don't even ask for the phy... physol... physiology, they just trust me.

When family members sincerely believe that the illness is real, they help sufferers to believe in themselves and in their own experiences, even when faced by others who disbelieve. Natalie made it clear in this account:

... dit is waar my ouers 'n groot rol gespeel het. Dit... dit was vir hulle tog baie duidelik dat... dat ek s... fisies siek is en *daar* het hulle my geweldig ondersteun, want hulle het my *oor en oor*... herinner aan... aan goed. Hulle sal vir my sê, maar, my kind, jy kan nie loop nie... so, dit kan nie net... jy weet, jy kan nie net jouself dit verbeeld nie.

For Natalie, then, the support of her family is a "protective shield" (Totman 1990: 153) which shelters her against the noxious and hurtful responses of the world outside the family.

A second and closely related element of "good support" which emerges from Helen's account is that of encouragement. By offering tender encouragement along the path to wellness, family members offer a valuable contribution towards a growing feeling of acceptance and especially of self-acceptance (Collinge 1993: 99-100). Natalie recalled such a gesture of encouragement:

So toe is ek nou uit die skool uit, ek onthou my ma het daai dag vir my 'n baie mooi briefie geskryf, ek sal dit nooit vergeet nie... mmm... om vir my te sê, jy weet, ek moet maar uithou en aanhou en geen muur is te hoog nie...

By this seemingly small gesture Natalie's mother helped her to confront and accept her new Self and her new limitations. For Natalie this made a difference.

Consider also Cheryl's heart-warming account of the limitless encouragement she experienced within her marriage:

... my husband has told me for ten years that I'm absolutely gorgeous... and he's been supportive in every way... He still tells me... almost daily that I am desirable... Even on an obviously awful day where my face is so swollen I can hardly open my eyes he just says: 'Darling, just remember you are sick, it's only temporary' – besides he adds, 'You're still sexy'! Isn't he a dear... I mean, he is *so* sweet in those ways...

Cheryl later reconfirmed this:

If it weren't for my husband, I'd feel devastated... My husband re-inforced it at all times that I was very attractive to him which did and still does help me so much to cope with this...

The endless encouragement offered so lovingly by Cheryl's husband directly mitigates the potentially devastating consequences of her suffering. It soothes the cares and eases the burden of illness.

Thirdly, Helen's account highlights the importance of open communication as another important element of "good support" within the family. Collinge (1993: 99) indeed identifies open communication as one of the most essential components of supportive relationships. According to Collinge (1993: 99), "this means honest sharing of feelings, wants, needs, and caring". Natalie strongly emphasised the value of communication of this nature:

... ek was so wonderlik geseënd om ouers te hê waarmee ek gedurig deur kon... gesels oor my siekte en hulle het altyd so ver hulle kon wyse raad aan my gegee.

For Natalie, open communication provided an opportunity to talk frankly and freely, to share emotions and experiences, and to seek advice that is often so deeply needed.

In addition, open communication also means that "parties feel free to say 'no' when they need to do so, without feeling guilty. In an environment of mutual respect there is freedom to be oneself without fear of judgement" (Collinge 1993: 99). Denise recalled her experience of such communication with her parents:

Ek dink hulle... hulle *luister* meer na wat ek sê... mmm... en hulle sal... hulle sal... hulle sal vir my vra, jy weet, wil jy dit doen of wil jy dat doen of... Dis... dis taai tipe benadering wat jy... wat hulle jou in ag neem... mmm... wat ek dink vir hulle 'n groot klemverskuiwing ook is... Mmm... so, hulle het meer begrip wat dit aanbetref...

Denise's experience reveals that within the context of open communication the freedom to express oneself often gives the sick person the precious opportunity to be heard and to be understood. Indeed, the opportunity to openly confide in another family member, to disclose the Self, may very well be extremely conducive for wellness and healing (cf. Totman 1990: 103).

Fourthly, Helen's description of "good support" highlights the important dimension of family support in practical matters. Natalie vividly describes such support within her family:

... dit het so geraak later dat my ma-hulle alles gedoen het... jy weet, my pa het my hare gewas en droog geblaas en hulle het... As daar nog mense gekom het, ek onthou dit so goed, het hy elke half-uur ingekom dan vra hy vir my kan hy nou maar my badkamer toe vat... en dit was... dit was baie moeilik, ek was baie siek...

In a similar vein, Natalie recalled:

... my ma het 'n punt daarvan gemaak dat ek... ek dink nie ek het een dag lank my... mmm... nagklere aangehad nie, ek het elke dag aange... ek was elke dag aangetrek, sy het elke dag my hare geborsel, sommer partykeer grimering aangesit (lag)...

Each instance of the practical support offered by Natalie's family is not only directed towards lightening her load but testifies to incredible sense of sacrifice and care. Cheryl confirmed the value of purely practical support within the marriage:

It's often said it's the little things that count and it really is. For example he brings my toothbrush, topped with toothpaste to my bedside as he does his own teeth before bed, because he know I... get tired standing at the basin... so I *sit in bed* and brush my teeth and only when they feel really good and clean do I have to go to the basin... Again to another family that would seem daft, but to me it definitely helps me cope!

Cheryl's experience shows that the practical dimension of family support directly concerns life where it is lived – in the home, in the sick person's bedroom – there where it is needed most *and* where it matters most.

Lastly, Helen's description of "good support" within the family stresses that such support is constant, endless, enduring, and unfailing. Participants repeatedly point to the importance of constancy of support, like Denise :

My familie was deurentyd ondersteunend...

So too, does Natalie:

My ouers het nog altyd baie ondersteunend probeer bly...

Cheryl similarly recognised the unfailing nature of her husband's support:

... my husband has never wavered... he has stood behind me 100%...

For each participant constant family support provides a basis of stability and a dependable haven. Both Collinge (1993: 99-100) and Totman (1990: 103) are of the opinion that support of this nature is likely to foster both physical and psychological security for the sufferer.

The other participants firmly corroborate those features which Helen identifies as the most significant features of "good quality social support" within the family context. These features combined to kindle a safe, secure and enduring environment where it becomes possible for ME sufferers to believe in and accept themselves, to express themselves openly and freely, and to receive reliable help when and where it is needed most. As in the experience of other chronic illness sufferers (Monks 1995: 462-463), it is this nurturing environment that not only lightens the load of their illness, but also lovingly encourages participants along their journey to wellness.

Cruel encounters

Unfortunately the participants do not only experience caring support within the family. On the contrary, they also encounter cruel disbelief and rejection among those from whom they expected it the least. Cheryl describes what happened to her:

My husband's family doesn't recognise ME at all... which has been difficult... I mean, his family has totally rejected it... When I got ME she (Cheryl's mother-in-law) decided that I was malingering and causing her son trouble... and... mmm... hasn't hesitated to tell everybody on that side of the family... and eventually... mmm... both... brothers, he's got two brothers, and their wives, verbalised the fact that they didn't believe that there's anything wrong with me and that I was just ruining the lives of my family... They make it obvious how sorry they feel for my husband and tell my children quite openly that their mother had better stop being lazy! And how sad they are for them all the time assuring them there is no such illness!

Cheryl reveals how this incredibly sad lack of understanding influenced her immediate family:

... all three children haven't been helped by my mother-in-law's... influence which was *much* greater than we realised, *much greater*. And the fact that she's so very good with the children, especially as youngsters... she was wonderful with them... So, I was delighted when the invitations continued to come when I... I became... ill... I was very glad that she would step in to do all those energetic things during a school holiday... So, I was grateful for that, but I didn't realise that she was feeding them a constant diet of, 'you poor children', you know, 'your mother just lies there, when is she going to pull herself together?'.

I didn't realise that until they got old enough to verbalise it... None of us knew it was happening. So, they... they've all gone through a time of... of *tremendous* crisis of deciding whether for them it's a real illness or not...

Cheryl experienced undisguised disbelief, disdain and rejection. Her husband's family could neither accept nor comprehend the nature of her illness. They thought that she was selfishly malingering, scandalously shirking her familial responsibilities, maliciously destroying the lives of her family. However, it was *their* ignorance and *their* lack of understanding which brought sorrow, hurt, agony and distress to Cheryl, her husband and to her children.

The participants also show that where there is no understanding of ME, inane advice abounds. Denise, for instance, recalled how her parents often responded to her illness:

Met tye... het hulle na 'n wonderkuur en 'n... as ek vir hulle sê ek is moeg of ek voel sleg, dan sê hulle nou maar drink net... sewe ekstra vitamienpille of iets in daai lyn, maar... maar jy besef dit is nie wat... wat no... wat gaan help nie... Ek dink met tye was hulle nogal ongeduldig dat... hoekom word ek nie beter nie... mmm... dit bly net aangaan en aangaan en aangaan...

Although such a response may be a desperate one born out of love for the suffering person, it adds tremendous strain to the relationship and increases the sick person's suffering (cf. Franklin & Sullivan 1989: 103).

The participants often interpreted those ignorant and inept responses from family members as pressure on them to recover – promptly! Natalie verbalised this experience:

... soms raak hulle baie moedeloos, geaggiteerd as ek vir dae min goed kan doen. My ma veral raak selfs kwaad, want sy wil nie hê ek moet ledig wees nie... Hulle raak bekommerd oor... oor al die tyd wat ek verloor, en soms raak hulle geweldig haastig...

When they do not understand the sickness and do not know how to respond to it, family members such as Natalie's parents at times become desperate, frustrated, and even angry. In turn, ME sufferers like Natalie experiences this response as pressure from family members *not* to be ill any longer, *not* to disappoint any more, *not* to tread the path of ME any further. Again, this unjustified pressure simply exacerbates their illness experience.

Each of the cruel encounters related above show that even family members have trouble in understanding the experience of illness caused by ME, and that this lack of understanding almost inevitably causes an inability to respond appropriately to those who suffer from this illness. It is reasonable to suggest that if family members had a better understanding of the

illness experience caused by ME, they would be better able to respond to the ill person. The combination of improved understanding and a better response will, at the very least, not aggravate the situation any further and, at the very best, may even alleviate the experience of illness of the afflicted family member.

In response...

The participants in this study could not but respond to the very real and immediate influence of their illness on the members of their families. Natalie clearly indicated this:

... wat 'n baie groot terugvoerende invloed op my het is die mense om my... en hoe hulle dit hanteer...

Very often the participants experienced a deep sense of disappointment, both in themselves and in their families. The source of such disappointment stems from the notion that they are incapable of living up to the expectations and role demands within the family.

Denise described the disappointment she experienced within the family context as she repeatedly failed to live up to her parents' expectation of recovery:

... ek dink... ook maar, jy weet, teleurstelling, want jy dink... sjoe, jy het nou dit en dit en dat probeer en dit gaan nou beter, hoekom gaan dit nou weer ewe skielik sleg? Of dan voel jy miskien... wat het jy nou weer verkeerd gedoen dat dit slegter met jou gaan? Het jy nou iets verkeerd geëet, het jy te veel stres gehad, het jy iets nie reg hanteer nie, het jy jouself ooreis of wat ookal... want, jy weet, jy voel soms dis jou skuld... en dan soms laat hulle jou verstaan dis ook jou skuld... En dit maak 'n mens nogal magteloos, want jy wil nie so voel nie en jy sal enige iets doen om te keer dat jy so voel...

Denise felt that she had disappointed her parents and herself. She questioned her behaviour, her actions, her choices. She felt confused and guilty, as though the unpredictable onset of yet another relapse was her own doing, her own fault. Sadly, she sometimes felt that her parents also held her accountable for the state of her health. This experience left her feeling helpless, powerless, and defenceless.

Natalie described a typical encounter with her parents, which revealed a similarly agonising experience of disappointment and frustration:

By tye dat ek beter is... dan... dan gaan dit nou, jy weet, dit gaan goed... en dan... dan sal my pa en my ma byvoorbeeld praat van... 'jy's beter'... en dit *frustreer* my geweldig, want ek weet ek... ek... ek *is* beter van... van die absolute akute stadium af, *maar* ek weet mos nou hoe ek voel en ek probeer mos nou maar hard om nie te veel te kla of wat ookal nie... en dan... *dan* maak dit my gefrustreerd, want ek weet more kan weer 'n dag wees waar daar 'n groot terugval kom...

Natalie felt intense frustration at the thought of not being able to live up to her parents' expectation of improvement and recovery. What if a relapse set in tomorrow? Would her parents feel disappointed? Would they hold her accountable for the sudden deterioration? Once again it was the unpredictable and uncontrollable nature of ME that presented numerous potential pitfalls of misunderstanding, and was also likely to induce a miserable sense of failure, frustration and disappointment in both the sufferer and the family.

Disappointment within the family also follow when the ME sufferer feels unable to live up to role expectations and demands. Cheryl emphatically disclosed:

... what still hurts very much is disappointing the children... and... my husband...

Cheryl offered a very illustrative description of the challenges she faced in attempting to fulfil her role within the family:

With the children it has saddened me greatly that I have not been able to host birthday parties – great 'extravaganzas' they used to be! I have not been able to be as effective in helping with school work either... I would dearly love to be more supportive. My husband says I am now that they are older because I am always available to talk and I write to all three of them at least weekly... But when they were primary school children it was really dreadful. My youngest hardly remembers a Mom that took part in everything... He hardly remembers all the entertaining, baking and cooking... Let alone the games we played... Another sad thing is that... while I still had two children at school... I had to give up making breakfast and being present for those early morning problems or worries that inevitably surface if something's been forgotten or an exam is looming that day. It simply became impossible to get up at 5:30AM with the family when I had perhaps had only 90 minutes of sleep or less! It was effectively ~~as~~ a broken 'night' every night for me... it became impossible to function... This saddens me still... Also the very real problem of my day/night sleep reversal pattern means special birthday breakfasts in bed are a thing of the past. Even on these special occasions everyone has to wait until I can 'function' – usually by 12 o' clock midday – sometimes later as I wake up very, very sore and slow moving. This frustrates everyone, I know... I miss an awful lot...

Cheryl's description cries of disappointment and frustration, of sadness and sorrow. Regardless of how hard she tried – and she did try – it was simply impossible to sustain the same nurturing role as she fulfilled before the onset of her illness. According to Crook (1982: 72-73) an intrinsic conflict may arise when the limitations imposed by the ME illness challenge the family care-taking duties dear to the sufferer. Under these circumstances, the sufferer is forced to confront the sheer inability to maintain adequacy of role function within the family. Cheryl experienced this inability to uphold her care-taking responsibilities within the family context as intensely disturbing.

Crook (1982: 72-73) also observes that "the power of roles is so great that it has been asserted that a person's perceptions, motivations, self-concept and psychological functioning are shaped and steered by the specific configuration of roles incorporated from society". Thus, the person's "configuration of roles" directly contributes to the nature, essence and meaning of that person's life – there where life is lived. It therefore comes as no surprise that when ME challenged and inhibited her nurturing mother role, Cheryl experienced a very real sense of loss.

The piercing awareness of loss repeatedly reverberates in Cheryl's story:

... they... they *have* missed out because I've been sick. I haven't *been* there all the times I've wanted to be there. I haven't *done* all that I've wanted to do... So, I feel sad for myself, but more sad for them. We have lost a huge chunk of our lives... to this illness.

It does too in Natalie's words:

Almal dink ek voel maar of ons iets verloor het in die proses... mmm... sjoe, dis mos nou nie wat ek mos vir myself beplan het in die lewe nie, ek is seker daarvan my ouers ook definitief nie... en dis is baie ontstellend... veral as... veral as jy niks kan doen nie, daaraan nie...

For Cheryl, Natalie and the other participants, the experience and awareness of loss within the family constitute a very real part of the experience of illness caused by ME. Franklin and Sullivan (1989: 102) suggest that "grief" is not too strong a word to describe the feelings that occur in a family touched by ME.

It is clear that, within the family context, the influence of their illness caused the participants in this study a multitude of confusing and disturbing emotions, of which the excruciating sense of disappointment, by both the family and by the participant, was very prominent. They could not live up to expectations. They could not fulfil role demands. The unpredictable and seemingly uncontrollable course of their illness posed a direct challenge to their very being within the family. Hence, they developed a real sense of loss, which became part of their human reality.

To cope...

The family of a ME sufferer struggles to understand and respond to the illness experienced by the afflicted family member. In turn, the ME sufferer experiences disappointment and failure

as it becomes beyond their reach to fulfil their role expectations within the family. These circumstances impose an onerous burden on relationships within the family.

After eleven years of illness Natalie sorrowfully concludes:

... na elf jaar voel ek al dat my eie huisgesin sukkel om my te ken...

She adds:

... ek weet my broer... mmm... ek het 'n broer gehad op daai stadium wat in standard 5 was, hy's nou al 22, hy ken my glad nie, ek dink nie so nie... Ons probeer baie hard werk aan 'n mooi, jy weet, broer-suster-verhouding, maar ek dink nie hy kan enigsins onthou wie ek was voor ek siek geword het nie... Alhoewel albei van ons nou baie ouer is en 'n mens se optrede verander tog met ouderdom, het my broer my leer ken as iemand wat altyd moeg is, altyd pyn het, te energieloos om mee te maak, iemand wat nie veel saam met hom sosiaal verkeer nie... in plaas van iemand wat vrolik is, besig, vol sports, talentvol, iemand wat omgee vir hom en wat hy doen. Die bekommernis is dat hy nie die ware ek sal kan sien deur dit alles nie, dat hy dalk sal dink ek wil nie graag sosiaal wees of belangstelling in hom toon nie, dat ek sommer net 'n 'ou tannie' van geaardheid is...

The strain and tension is obvious. Because there virtually never was a moment without ME in their relationship, there never was a moment in which Natalie could reveal herself to her brother as she felt she really was. Equally, there never was an opportunity for him or the rest of her family to really get to know and appreciate her for herself. Sadly, this left Natalie to feel permanently misunderstood, held captive by the bounds of her illness.

Cheryl related how she experienced strain and tension in the family:

... while I've been sick... things have been a bit of a strain on the children as well because... mmm... if I had been... irritable... because I was in pain and I don't know what to do and I can't move and I really need help just to get to the bathroom and I'm not wanting to ask for it and I'm being stubborn... and... mmm... then he'll say something simple like, 'what's for supper'... and I'm thinking 'I'm about to die and this man wants supper'... you know... and then my reactions will be all wrong and then he will go and get irritable with the children... tell them to 'tidy their rooms' or 'start studying' or 'go and clean the kitchen' or 'haven't someone unpacked the dishwasher' or whatever... So, it's a... it's actually a... sometimes a very awkward situation... We have... have tremendous blessing in being a happy family 90% of the time, but there's a... there's a good fat 10% where the... wheels come off... there's no doubt about it, where our family suffers directly because of the fact that I'm not able to fulfil my role like I used to...

Cheryl has this to say about her "dearest and nearest relationship" :

... I was finding myself becoming a bit short-tempered and irritable, which I... which is still a problem... which... which was difficult for the kids, but... nooo, not really the kids, it was more my husband who suffered, because with the kids I do my level-best to keep up pretences until bed-time... and then my husband would have me collapse on him after the kids were in bed... and then I would say ridiculous

things... mmm... I don't know now anymore... but... I would blame... I would... I would bring up a conversation that would end up blaming him somehow for the fact that I was in a heap... I don't know how I did it, how... eh... how... convoluted it could have been, that this poor guy received the worst end of my day... but... it always was... mmm... in my worst times... it always ended up with me taking it out on him or... or just collapsing on him...

ME issues a challenge very few families and very few couples are prepared for. It causes unpredictability, sudden severity, irrationality, ridiculous reactions, and uncertainty. As a natural result the ME sufferers in this study, as well as persons who suffer from other chronic and severe illnesses (cf. Dyck 1995: 311-312; Monks 1995: 463-464), experience that family relations become stressed.

Still, for many ME sufferers the family remains the pivotal point of interaction. They are ultimately part of a family and regard amicable family relations of indispensable value. This is equally true for the participants in this study. From their accounts it is evident that they try to appease tension and to inspire harmony. This effort firstly involved adjustment, and secondly demanded a special effort.

Adjustment within the family particularly involves accommodating the sufferer's limitations which are imposed by the illness. Consider Cheryl's very illustrative account:

At the moment it is already past 3am. For (my daughter's) birthday tomorrow I am desperate to feel rested but, and here I confess, even a double dose of sleeping tablets has had NO EFFECT. So she'll only see me late tomorrow morning – if I am lucky and manage 7 or 8 hours (fairly rare). She'll only see me to open presents etc. at midday... we have tried to adapt family life to my sleep pattern as unfair as that seems and even the birthday boy or girl who gets their choice of favourite breakfast at lunchtime... Most families would think this DAFT – but that's one eg. of how we cope.

Cheryl's day / night sleep reversal pattern demands adjustment from the whole family. "Daft" as some of these adjustments may seem, it works for them.

Cheryl noted a further unfortunate consequence of her day / night sleep reversal pattern that is even more upsetting because it affects her most cherished relationship:

The worst effect of this is that about 4 months ago we came to the conclusion that my husband could no longer cope with my tossing and turning and frequent need of my little torch to find a tissue or something and I couldn't cope with so many hours trying to lie still in the dark! So he uses the spare room bed after ±10pm. We still spend the early evening together in bed but we hate sleeping apart, but can find no other solution. My husband was so exhausted by the disturbed nights next to me. At first we tried moving me to the spare room so as to make getting dressed for work easier for him... but I found I collect

SO much around me during the day that to move all that each evening, down to a jug of water & glass, medication, reading or writing materials... and so on, just too much. All he needs is fresh work clothes... he doesn't need anything else to while away the night ~~tho~~ like I do.

Cheryl's account lucidly illustrates a lamentable yet essential adjustment in family life caused by the constraints imposed by ME. Without adjustments of this nature, neither a marriage nor a family would be able to master the challenges posed by ME.

In addition, adjustment to the limitations of the ME sufferer often involves the redistribution of responsibility within the family. As Natalie admitted:

... die ander ding is... prakties gesproke... partykeer het ek sulke groot terugvalle dat daar... daar is goed wat ek moet doen wat ek nou nie kan doen nie, dan moet hulle dit doen... So, dit raak hulle onmiddelik.

When certain tasks and responsibilities fall beyond the ME sufferer's reach, the family needs to step in. The sufferer's responsibilities become the family's responsibilities.

Cheryl provided a further example of the redistribution of responsibilities within the family:

... often after a long working day he has to pack the dishwasher, make something to eat... load the washing machine etc etc and... and start doing things, which I'm *sad* that he has to do, I would rather he didn't have to...

Mundane as these tasks may seem, being able to count on someone to do them makes a huge difference to the sufferer. After all, for an ME sufferer like Cheryl who was used to running the household efficiently, the worry of lapsed housework and overdue tasks might prove to be unendurable at times. Hence, as the family lifts the burden of responsibility from the sufferer's shoulders, they offer the sufferer the space to get better without any undue worry or stress (cf. Dyck 1995: 314; Franklin & Sullivan 1989: 104). Making the required adjustments within the family therefore may pave the road to wellness for the afflicted sufferer.

As is clear from the participants' accounts, adjustment within the family is often accompanied by a special effort on the part of the sufferer. Such special effort is neither disguised as a bribe nor intended as a subtle way of saying "thank you", but it is rather an effort to aid the family in coping with ME, despite the odds. Heed the sentiment as Cheryl expressed it:

Also a very good thing to do is simple and easy and energy saving treats for your family. You know you aren't cooking and baking like you used to, so listen carefully and try and pick up what their current favourite sweet is, and then... put one of these treats on their pillow... Really anything that shows you've

listened and care. I include this as a way of coping with ME because to hold a family together during this sort of strain is only by God's grace and His wisdom.

On a more intimate level a huge special effort was required. Cheryl explained:

As far as a sexual relationship goes there are a host of obstacles! Anti-depressants reduce your desire or your ability to achieve orgasm – as do some other drugs. On top of that your body is often just too sore to move! We have worked out successful positions and very seldom leave a long patch without intimate relations... If is also important to the 'patient' as you must endeavour to continue to feel attractive and desirable and this also reinforces your worth as a person... We set whole weekends aside to be completely alone and this is very valuable. Sometimes I spend that entire weekend – booked somewhere in advance... sick in bed, but sometimes all goes well and we feel almost 'NORMAL' again.

She candidly added...

... another thing that helps a married relationship – especially one that needs a bit of extra effort due to my circumstances, is buying 'sexy' underwear to surprise my husband. You won't believe this, but on our last weekend away... I managed to be alone... and bought a red lacy bra and matching panties! Can you believe fat and middle-aged doing that... And was my dear man just bowled over! And he so appreciated the effort and the surprise.

Cheryl's account reveals that ME imposes restrictions in all spheres of family and marital life. These restrictions in many cases require a "remaking" of the lives of the ME sufferers. Part of this "remaking" involves what Ware (1999: 319) calls a process of "downshifting", of cutting back and doing less where possible. Yet, to do so demands special effort from the sufferer. While activities considered disposable are summarily cut, those regarded as essential to the well-being of the family and to married life are still very deliberately pursued.

Often the attention given to adjustment and special effort creates an environment that allows each member of the family to deal boldly with the influence of the illness. Moreover, in dealing with the illness and its consequences, the family is more often than not drawn closer together. Natalie gave expression to this experience:

En dan die ander... ander sy daarvan is weer ons het 'n goeie verhouding *ook* daardeur opgebou, omdat... mmm... hulle is basies al wat ek het, die enigste mense waarmee ek... *reguit* kan praat, jy weet... en ek kan vir hulle sê, kyk, dit is *rêrig* hoe ek nou voel en ek weet julle kan niks daaraan doen nie, maar... dit help my net as iemand miskien dit hoor... Daar is positiewe en negatiewe dinge daaraan, want wat hulle vir my sê raak my natuurlik *baie*, omdat hulle... hulle invloed is groot, jy sien, omdat dit is... dit is die persone wat ek het. So, hulle kan... mmm... jou positief beïnvloed of negatief beïnvloed, jy weet, jou seer maak of... positief beïnvloed en help om die ding in die gesig te staar en te weet jy het so ver gekom, so jy kan verder gaan.

Natalie's account, which closely corresponds with the experiences of the other participants, powerfully illustrates the central position which the family of the ME sufferer occupies. Indeed, the nature and content of relations within the family can steer the sufferer towards either hurt or healing. Hence, the family's influence on the ME sufferer and his or her experience of illness cannot and should not be underestimated.

ME evidently places a substantial burden on the relations within the family. It is indeed the very nature of ME, its unpredictability, severity and uncertainty, which challenges both the family and the sufferer. To respond to the challenge and to cope, the family afflicted by ME adjusts to the constraints and consequences of this illness, while the sufferer contributes by making a special effort. In this way, in their intimate alliance, the family and the sufferer grapple with the strange illness in their presence. They try, endeavour, attempt, strive, and they cope, as best they know how.

Conclusion

The family is important. This is the undeniable conclusion reached by the participants in this study. Perhaps the family is no longer the absolute pivotal basis of social interaction as it once was, but for the ME sufferer its eminence and influence is certainly far from negligible, let alone extinct.

The participants were also deeply aware that, as they suffer from ME, so too does their family. More importantly, the participants realise that their families exert a powerful influence on them and on their experience of illness. They realise that with the help of their families they may reach their destination of wellness whereas, without it, they will loose their way.

Hence, the participants earnestly ask their family, "Believe me and believe in the reality of my illness; talk to me and let me talk to you; encourage me and always be there for me; do not judge or reject me; do not demean my illness through unsound advice; help me not to feel so useless and helpless; help me to find new ways to be with you, to be part of you; and please, please, try to understand me".

When the family of a ME sufferer responds to this call, profound adjustment and sacrifice follows. In turn, sufferers try to lighten the load assumed by the family by helping, by

contributing, and by making a special effort. In an intimate union the family and the sufferer construct a protective shield which can blunt the potentially harmful effects of the illness in their midst. It is an all-encompassing security that is carried forward from within the family into the rest of the sufferer's life.

Where the family and the sufferer fail to create a unity of defence against the ravages of ME, the sufferer's journey to wellness is blocked. Conversely, where the family and the sufferer succeed in joining forces, the sufferer's journey to wellness is likely to prosper. Thus, for ME sufferers, their family *is* important; for ME sufferers this is their human reality.

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Chapter 13
Friendships – Firm and frail

Strauss and Glaser (1975: 58) state that "the chief business of a chronically ill person is not to stay alive or keep his symptoms under control, but to live as normally as possible". This is the very human reality of all illness and especially of chronic illness (Atkin & Ahmad 2000: 509) and it is also true for the ME sufferer. After all, every ME sufferer desperately wants "to live as normally as possible" – despite the illness, the symptoms, the limitations, and despite the adjustments.

For the ME sufferer, as for any other individual, an essential element in the pursuit of such a "normal life" is friendship. However, how is friendship affected by exposure to the realities of ME? Do friendships endure or do they fail? An answer to this question will contribute towards better understanding how the ME sufferer subjectively experiences the human dimension of friendship, and of illness

Nurturing wellness

The participants in this study painted brilliant word-pictures which glow with the treasured kindness, care and support that they received from very special people in their lives: their friends.

For the participants these special people were the ones who tried to understand and who accepted them as they were… illness, symptoms, limitations, adjustments and all! Helen very specifically emphasised the effort to understand:

My close friends who I value as special friends, were... very supportive and tried to understand, although I was aware it was difficult for them at times as I was not my energetic, enthusiastic self...

For Helen just the mere attempt to understand, to gain some insight into her situation, difficult or even impossible as it may be, showed that her friends cared. It convinced her of their support.

As Helen found comfort in the very attempt to understand, so did Cheryl discover delight in unfettered acceptance:

The best... the best... the best... the best are those who... who... who *don't* need *any* explanation, but accept me... accept me exactly as I am. You know... accept the fact that I no longer bake and cook and fuss around like I used to be able to do for them, accept the fact that the house is generally dirty and dusty and... that sort of thing... and they just accept it... Those are *the* best people.

Cheryl's words truly burst with delight! In the best of friendships she had discovered an infinite acceptance that demands neither explicit understanding nor flawless fulfilment of previous standards.

Now, consider Denise's emphasis on the rewarding combination of understanding *and* acceptance:

... soos ons was nou weg vir... vir 'n naweek en... en as ek moeg was het ek eenvoudig gaan lê en slaap... Dis half asof hulle verstaan het... So daarin het 'n mens 'n mate van vryheid ervaar dat hulle... en begrip... dat hulle... besef jy... sover as wat jy kan dan doen jy mee, maar as jy nie kan nie, *dan kan jy net nie*... dit... dit maak vir my 'n groot verskil...

Indeed, it made a difference. In the combination of understanding and acceptance Denise found freedom: the freedom to be, even when that freedom included being ill.

For the participants their valued friendships were also characterised by tender encouragement. Denise described her experience in this regard:

... jy het vriende wat by jou staan regdeur die hele storie... Jy kan hulle miskien op jou twee hande tel, maar hulle is daar en jy weet... ... maak nie saak wat nie hulle sal by jou wees... Mmm... so dit... dit... dit het my baie bemoedig...

Denise experienced encouragement in knowing that her friends where *there* – regardless (or perhaps in spite of) her state of health.

Natalie also shared her experience of encouragement within her circle of friends:

Ek dink ek was baie bevoorreg ek het 'n groepie vriende gemaak wat baie lief was vir my... en mmm... baie trots was, want hulle kon sien ek sukkel... My... my een vriend spot... mmm... ek kom in die klas dan bewe ek verskriklik, dan sê hy vir my, oeg, vandag gaan jy darem lekker skets, jy weet, jy kan lekker daai potlood so laat skets... Jy weet... mmm... ek sou nie vir hom sê nie hoekom nie, maar hy kan dit sien, ek bedoel, dis baie ooglopend... So dit was goed, want in daai opsig het ek... humoristiese ondersteuning gekry en... ek glo natuurlik hulle is almal engeltjies...

Natalie's heart-warming experience portrays the jubilant victory of witty humour over the obvious pain of a distressing illness. It was encouragement of this nature that inspired Natalie to celebrate her friends as little angels – little angels who lightened her load and paved the way to wellness.

Thirdly, the participants ascribed great value to open channels of communication within friendships. Cheryl gave expression to this sentiment:

The friends that still ask and actually want an answer are very s... precious and... even if they don't understand a word I'm saying, if I need to talk, they'll let me talk...

She later strongly reiterated:

... there are definitely some of those who are interested enough to set aside time to talk to me... and they are... they do listen... they remember what I say... they phone me back... and I appreciate that enormously...

Cheryl found in open communication a freedom to express the Self, a freedom to be listened to without fear of intolerant or opinionated judgement. Thus, when friends made an effort – to listen, to remember, to reply – it was noticed, welcomed and deeply appreciated.

Fourthly, the participants in this study strongly emphasised the importance of practical support. Natalie gave a pertinent example:

Toe ek, byvoorbeeld, geswot het... mmm... as ek nou vir twee weke nie meer by die Tech kan wees nie, dan kom daar nou groot probleme, jy weet... my vriende moet begin... goeters organiseer om my te help en... uit hulle pad uit gaan...

Natalie's friends made a special effort to lessen the load of overdue work and ease her return to the course. Without such invaluable assistance, Natalie might not have been able to complete her studies and, hence, to pursue her vision of "normal life".

For Cheryl, practical help and assistance from friends made a tremendous difference:

... in the beginning, friends, family, acquaintances, the church, everybody rallied round, I mean, there was just a constant flow of meals, and visits, and flowers, and everything, and it was... obviously very heart-warming... I mean, all of that, it made an enormous difference that I had support from everybody...

Even today, eleven years later, Cheryl still enjoys such support from special friends:

There... there's one family that... that *never ever* come without a meal... They come *at least* once a month... and *always* bring food with them. That's... enormously kind. And they don't know a thing about ME... So, golly, we're greatly blessed!

These instances of practical support testify to an exceptional degree of care often found among the friends of a ME sufferer. It is exceptional for it flows forth even in the absence of insight into the illness. It requires no reason or understanding. It is offered in simple, unqualified kindness.

The last quality in friends that the participants highly valued is dependability. Cheryl offered an example of unwavering dependability among friends:

... good friends have stayed good friends and we could call on anyone of them at anytime of the day or night should we need help.

Denise substantiated this:

My vriende het my deur dik en dun bygestaan...

Any time, any day, any situation... support is there, unwavering, unflagging, unfaltering. For the participants this is the essence of dependable support among their friends.

Thus, through vivid word-pictures, participants in this study depicted the invaluable treasure of support found within friendships. The qualities of this treasure – understanding and acceptance, encouragement and communication, practical help and dependability – are unconditional, undemanding and unwavering. For participants, this treasure of support provided the freedom to be and express the Self on the road to wellness. It provided the peace of mind, the certain knowing that along this road there will always be special people – there will always be friends.

Cruel encounters

The experiences of the participants in this study revealed that not all friends were supportive. From some so-called friends they actually experienced cruelty.

For the participants cruel encounters with friends stemmed from one focal point: a dire lack of understanding. Cheryl recalled an experience that epitomises such ignorance:

... we were all home... and... something made my husband open the front door, and at the front door was a television and a video... and... a note from the minister of the church saying that he thought that we would find this useful... we saw the note and thought, 'oh, that's very kind of him... it must be something up-building or interesting or whatever'... It turned out... it turned out to be a video produced by the AA... and... mmm... the characters in the story had children exactly my age, husband and wife

with... children verging on their teens... and... and a mother who was a alcoholic... I couldn't believe it... I howled my eyes out throughout the whole movie, because it wasn't... mmm... even a victorious... battle over alcohol... So we... were absolutely shattered... I presume that they thought I was a secret alcoholic... or they thought that I was... mmm... endangering my family by pretending to be an invalid... that would be the charitable view... the less charitable view is that they thought that I was a secret addict of some sort... So we invited this chap now, this minister, to come and talk to us... and he came round... and... he said that... he just wants us to know that that video wasn't just from him, that there were ten other people in the church who got together and decided that it was applicable to our... our... life at the moment... and that we needed to be jolted back into reality, to realise what was hap... what I was doing to the family was so destructive. We just sat there with our mouths open, we didn't know what on earth he meant... I mean, obviously, I realised that my illness was not bringing... mmm... great joy into the family... Our family was suffering trauma... and... it was being heightened by what the community was doing to us...

This account cries out bitterly against ignorance! Certainly there is nothing more frightful than ignorance in action! It was in ignorance that Cheryl was blatantly accused of addiction and that she was accused of destroying her family life. It was in ignorance that she was called to acknowledge "reality". It was in ignorance that she was shattered.

It is no wonder that such experiences, recounted by all the participants, repeatedly led them to the conclusion that some friends (perhaps even most friends!) would never understand or share any real insight into their situation. Consider Natalie's statement:

My vriende verstaan nie... Ek kan nie sê ek het *een, een*, maar *een* vriend of so wat al ooit moeite gedoen het om, byvoorbeeld... intens met my daaroor te gesels of my uit te vra daaroor of miskien iets te wil lees daaroor nie... ek weet nie of dit s... hulle sou *help* nie, maar dit sou miskien vir hulle 'n bietjie *insig* gegee het. So, ek dink ek kan sê hulle doen baie moeite om dit te verstaan nie... Mmm... en die vriende wat ek nou maar gehad het toe nou toe... hulle het nie juis veel... veel omgegee daaroor nie...

Natalie's account contains a sharp sense of disenchantment. Her friends did not understand, let alone try to understand. For Natalie this conveyed one clear message: they simply did not care.

Natalie continued...

Voorheen was ek nooit tussen mense nie, toe ek nou tussen mense kom, toe sien ek hulle reaksie teenoor my siekte... wanneer hulle geweet het daarvan, het hulle dit hanteer in onkunde, in die sin dat hulle maar altyd gedink het dit is in my kop... op 'n manier... mmm... al het jy flou geval voor hulle, sou hulle oortuig wees daarvan dat jy nou weer te lui was of iets... Daar is baie... wat my nou nog 100% in twyfel trek as ek vir hulle... sê ek... mmm... ek voel nou siek... dis die faset waar mense onkundig is en... hulle raak lelik met jou...

Ignorance is, thus, as Natalie sadly discovered, often accompanied by two treacherous companions: doubt and disbelief.

Helen all too frequently encountered doubt and disbelief amid her friends' response to her illness. She sadly related that her friends…

… clearly did not have any idea of what I was going through and… reacted in very strange ways… they reacted with anger, disbelief and resentment…

Unfortunately, this response often translated into added anguish for the sufferer:

On numerous occasions, I was told I should eat more, as I had lost a lot of weight… and there were rumours that I was anorexic or bulaemic…

Denise related a similar experience of friends reproaching her:

… hulle het nie altyd verstaan nie, hulle dink jy is nou maar… up-stairs of jy… is 'n swot-freak of wat ookal, maar intussen wil jy net jou deur toemaak en op jou bed lê…

Instead of much needed understanding, Helen and Denise were challenged with recurrent criticism and even ridicule. These experiences simply served to amplify their suffering. Indeed, for all the participants their friends' callous ignorance of and deplorable response to their illness at times appeared almost unbearably relentless.

And relentless it was – the participants' experiences within the context of friendship were exacerbated by an awkward logic that appeared to be at work among their friends. This logic allowed even the most blatantly ignorant of her friends to discharge a barrage of advice onto the poor sufferer.

Natalie repeatedly experienced this logic. She vividly described the ludicrous advice which saturated such confrontations:

… as hulle nou begin weet wat jou probleem is, dan is daar weer ander goed wat by kom… byvoorbeeld… mmm… ons het gehoor hierdie siekte is maar net alles in jou kop… ons het gehoor jy het nie genoeg dryfkrag nie… of ons het gehoor… jy weet… of ons vriendin was 'n week lank was sy… het sy yuppie flu gehad, maar sy's nou beter, jy moet na 'n ander dokter gaan… En toe daai stadium verby is, het die… het die nuwe stadium begin en dit was van… jy moet positief dink… pain is gain (lag)… mmm… jy weet… ag… lig jou kop op… eh… jy weet… het jy al ooit… mmm… na musiek geluister wat jou kan kalmeer?… worry jy te veel?… daai tipe van ding, jy weet… Ek het elke dag, elke liewe dag van my lewe as ek by daai Technikon kom is daar iemand, ek weet nie elke dag wie dit gaan wees nie, maar dan is daar iemand wat vir my 'n klein prekie afsteek…

Denise also vented her intense annoyance and displeasure with the inane advice so frequently offered by the ignorant:

Wat 'n mens ook half frustreer het is... as jy sê jy het ME dan... dan het *almal altyd raad*, jy weet, hierdie broerskind of daai suster se vriendin se dogter het dit ook gehad en sy het net appelasyn gedrink elke oggend en sy is beter, jy weet, of hierdie broer se seun het dit gehad en hy het elke dag drie glase wortelsap gedrink en hy's nou heeltemal gesond.... Jy weet, dat hulle sulke... *sulke* raad vir jou... almal dra vir jou raad aan, maar... en almal neem jou kwalik dat jy nie hulle raad gebruik nie, maar jy kan net nie...

This inane advice may eventually even include religion and the concept of salvation. Consider Natalie's account:

Ander mense gee nie raad nie, hulle verkwalik jou; hulle beskuldig jou; hulle preek vir jou. Hulle vertel jou jy is skuldig aan jou eie lot, want jy is 'n negatiewe persoon; jy is 'n pessimis; jy ken nie diepere waardes en reëls van die lewe nie. Ek het al selfs gehoor ek is nie God se kind nie of ek glo nie genoeg nie...

Cheryl expressed a sense of perplexity in the face of a similar approach among friends:

Even Christians who tell me that this can't be from a loving God and if God hasn't healed you, then... you need deliverance from satanic powers. Golly! How can that be?

Denise offered a more elaborate account of the chiding received from friends:

Jy kry die mense wat dink... jy weet, wat die benadering het van... 'kom ons bid vir jou en jy gaan gesond word en as jy nie gaan gesond word nie is daar een of ander iets in jou lewe wat... wat keer dat jy nie gaan gesond word nie'... En mense wat in jou verlede grawe... en die een moet jy nog vergewe en daai een moet jy vryspreek en daai sonde het jy gedoen en as jy nou met al daai goed gaan breek en dit gaan hanteer dan gaan die Here jou genees... jy hanteer nou maar wat jy moet hanteer, wat hulle sê jy moet hanteer... en later aan besef jy, maar, dit is nie die oplossing nie... op 'n stadium moes ek daai mense vergewe dat hulle so half jou... jou onder veroordeling plaas...

Well-meaning advice perhaps, but undoubtedly tormenting.

What assistance could there be in judging a person as simply not positive enough? What sense could there be in telling a severely ill person to enjoy a glass of carrot juice? What logic is there in preaching deliverance from evil powers?

Within the context of friendship, sanity had apparently succumbed under the onslaught of ignorance.

The fragile nature of friendship was demonstrated by the sad tendency among friends of the ME sufferer to distance themselves from their ill friend. When their friend needed their help and support the most, they chose to look the other way. Natalie sadly told of this experience:

My beste vriendin het my geheel en al... jy weet, sy het eendag vir my gesê as ek nou nie my humor terugkry en begin lag en so... dit was nie 'n kwessie van humor nie, dit was 'n kwessie van ek het nie krag eers om... om humoristies te wees nie... en... en sy het my geheel en al in die sop gedrop, sy het net, jy weet, heeltemal haar gedistansieer van my, ek het haar nooit weer gesien nie, tot vandag toe nie...

Natalie's friend did not understand. She responded in ignorance. And her response was cruel.

Cheryl also came to know such cruelty. She sadly recalled the attempts friends made to distance themselves from her and her strange illness:

The few friends we still had left... they decided that... they were not going to offer help anymore, because... mmm... I was obviously... it was weird, it came across in such a weird way... they decided that if they carried on helping our family, in any way, by providing meals or anything like that... they were... mmm... encouraging me to become an invalid... Three ladies phoned me and gave me this information... all of whom... didn't know my situation at all, who just were people in the church community who had come under the influence of what the minister had now decided was best for our family... And another two ladies, who I considered very close friends, came to visit me... to pass on this information... and now... they were all going to help me get out of invalid-mode, tough-love sort of thing, you know... And... at that stage, to be honest with you, there wasn't much help forthcoming, because we were over the initial period where no one knew what was wrong and I was desperately ill... So there wasn't actually a steady flow of help... I mean, we were now already... mmm... seven years into the illness... there weren't people rallying around at that point... so why they even had to make this... statement at that point I don't know... don't know what prompted it, I can't imagine what prompted it... I mean... they weren't bringing us meals or anything like that, we were just really struggling very much on our own... nobody seemed to want to have anything to do with us anymore...

Cheryl's friends deliberately endeavoured to create distance. Perhaps, in some sense, it is a comprehensible reaction. They did not understand the illness and did not know how to respond to it appropriately. Hence, to avoid embarrassment and failure, they avoided the illness and the sufferer. Perhaps it is understandable, but the fact remains that when the ME sufferer needed their help the most they deserted the friendship. They left their ill friend in the cold void of friendlessness. How could this be anything but fiercely cruel?

It is quite clear that the cruelty of the participants' friends originated from an incredible lack of understanding of this strange illness. Indeed, in the face of the inexplicable, their friends made false accusations, reached wrong judgements and lavishly dispensed senseless advice. When

this approach accomplished little, they often abandoned the friendship. In this manner insane ignorance ruled and bitter cruelty prevailed.

In response...

Participants' response to their encounters with friends reverberated with a strong sense of tribulation. See how this shines through in Natalie's words:

... ek dink die *sosiale* aspek van die siekte en die siening van mense en hulle reaksies op jou is 'n *baie-baie* groot euwel. Dit is tot 'n mate meestal negatief; dit is soms kru; dit maak... seer al moet dit nie...

For participants such as Natalie this sense of tribulation became manifest in the very tangible experience of isolation. Within this context, isolation can be regarded as the result of a two-fold process: firstly, friends withdrew from sufferers, and secondly, sufferers retreated from friends (cf. Field 1976: 348).

Friends withdrew and were, hence, lost to the sufferer, because the ill person had changed. This change primarily involved a physical inability to sustain friendships. Denise explained:

Jy het baie vriende ook verloor in die proses... mmm... omdat jy nie in staat is om vriendskappe rêrig in stand te hou nie... en baie mense verstaan dit nie... jy... jy is *fisies* nie in staat... nie... mmm... wat *sleg* is, want jy verloor goeie vriende langs die pad...

Natalie voiced a similar concern:

Jy weet... ek voel... ek s... wanneer ek 100% in 'n vriendskap insit, dan lyk dit net soos 10%, want ek kan nie... eh... ek kan nie alles meemaak nie...

Natalie's statement emphasises the fact that an inability to sustain friendships is closely bound to an inability to actively *participate* in friendships. This important point is further clarified by the following experience related by Natalie:

... ek het ook van my vriende verloor, want dié van hulle wat met my kon identifiseer of waarmee ek kon identifiseer... hulle het ook behoeftes om sekere goed te doen, byvoorbeeld, hulle gaan naweke weg plaas toe... En die... die inspanning van so iets is vir my te groot om te sit saam met my studies, so ek moes kies... Ek kan tien teen een dit gedoen het, ek kon tien teen een 'n naweek saam met hulle plaas toe gegaan het... maar ek het besef as ek Maandag wou T..Tech toe gaan... so... daar... daar het afstand weer begin... Ongelukkig... het ek heelwat vriende verloor as gevolg van dit, ook moontlike vriende wat ek nog kon maak...

Denise described a similar experience of physical frailty foiling friendships:

Dis nie altyd lekker nie... as jy 'n hele naweek beplan het en jy kom op die Donderdag by die huis en jy besef, kyk, ek gaan eers Maandag opstaan... mmm... Dis swaar, want dan moet jy... dis weer waar die vriendskappe inkom, party mense gaan verstaan as jy hulle bel en sê, ek is jammer, maar ek kan nie... ek is moeg... of wat ookal... en ander sal sê, ja, maar lê 'n uur en dan is jy reg... en dit is nie so nie... So, jy kry mense wat verstaan en mense wat nie verstaan nie... partykeer maak dit jou seer dat jy... dat jy weet jy verloor vriendskappe daardeur...

Sadly, Natalie and Denise's experience of loss, caused by sheer incapacity, was shared by all the participants. Their friendships were disrupted and often disintegrated under the impact of reduced energy, impairment of mobility, bodily restrictions, symptom management, and the like (cf. Strauss & Glaser 1975: 54-55). For them, ME brought limitations and adjustments which hindered participation in and enjoyment of friendships. For them, ME brought loss and isolation. This experience is, as Kelly and Dickinson's (1997: 260) study shows, not uncommon among those who suffer from severe chronic conditions. In their study, respondents who suffer from ulcerative colitis (chronic inflammation of the large bowel lining) reported the experience of friends having moved on in their lives leaving them feeling "very friendless" and almost isolated for protracted periods of time.

Yet, besides a change in the physical ability of the sufferer, the fate of friendships was also notably influenced by an intrinsic change in the Self of the sufferer. For Natalie, this realisation unfolded as follows:

... ek kan tereg sê ek het heelwat vriende verloor, omdat dit heel moontlik is dat 'n mens as persoon heelwat verander. Wat ek was en wat ek is... daar is verskille. Baie van 'n mens se vriende sukkel om dit te hanteer... Die rede is dat daar so 'n groot verskil kom... daar is so 'n groot verskil tussen hoe jy was en wie jy nou is... eintlik... hoe kan 'n mens eintlik aangaan, 'n mens verwag ondersteuning van 'n vriend deur dik en dun, maar dit is nie meer dieselfde vriend eintlik nie, die persoon nie, dit is so groot verskil...

Thus, when the ill person changes and relationships cannot be renegotiated on a new basis, an experience of loss and isolation is almost inevitable (cf. Crook 1982: 73).

Just as friends withdraw from the ill person, so too does the ill person retreat from friends. In fact, they do so for exactly the same reason: there is no remaining basis for friendship. Yet, there is a different emphasis in each party's reasoning: for friends, the basis of friendship has been negated by the sufferer's inability to participate in the friendship as before; for sufferers,

the basis of friendship has been ruined by their friends' inability to understand or at least accept their situation.

Share Natalie's experience of retreat from friendship:

... ek het nou iemand gehad by die Technikon wat my gedurig deur... dis asof sy my uitgesoek het elke dag om vir my te sê ek moet 'n meer positiewe ingesteldheid hê en ek moet meer geloof hê en ek moet... En ek het later, omdat ek *nie geweet het* hoe om vir haar... te... te laat *insig* kry en... en... en te laat verstaan dat ek al daai dinge probeer en dat dit my *nie* gaan help as sy my raad gee elke dag nie, het ek my begin distansieer van haar, jy sien, ek het haar begin vermy... Dis *al* wat ek kon doen...

Helen's words reflect a similar notion of defection and evasion:

I became extremely sensitive to their comments and responded by isolating myself even more... in order to protect myself...

For Natalie and Helen as well as the other participants a vicious cycle was grinding its way through their friendships: the less understanding others showed towards them and their illness, the more isolated they felt. Yet, the more isolated they became, the less likely it was that others would understand and the less likely they were to experience any understanding. For the participants this constituted the way in which the illness had built (and still builds) a wall of isolation between them and their friends.

Each time cruelty is encountered this wall of isolation is strengthened. And each time, the sufferer resolves not to talk about the illness any longer, to anyone. The sufferer desperately wants to protect the Self from the cruelty, from the hurt it carries. A tone of desperation resounds clearly in Natalie's account:

En ek dink... ai, dit het my seergemaak... ek was baie seergemaak... mmm... baie dikwels... En waar ek miskien voorheen my mond sou uitwas, vir hulle 'n goeie storietjie sou vertel, het ek gevoel... maar die siekte is nie iets wat ek kan rondslinger nie, dis nie iets wat jy... jy kan dit nie aan iemand verduidelik nie, jy het miskien nie die krag om dit aan iemand te verduidelik nie... en jy sien later nie eers meer die sin daarin nie, jy wil dit graag wegsteek, jy wil dit graag weghou van mense af... mmm... veral as gevolg van die onkunde...

Natalie later sadly added...

... die feit dat daar so *baie* negatiwiteit is en so *baie* wanbegrip is... dit affekteer my *baie*, op hierdie oomblik, nou nog... mmm... net omdat dit moeilik is om... uit *niks* uit vriende te maak... van *niks* af nie... omdat daar klaar... daar is klaar baie kere saadjies geplant... ek vind dit *moeilik* en ek vind dit moeilik om... van myself te gee, omdat ek bang is ek kry seer, want ek het al baie seergekry. So, ek maak baie minder oop, dink ek...

Natalie's words reflect the sadness of defeat in the face of a seemingly invincible ignorance. In response, she closed up and she reduced access to the Self. For an ME sufferer such as Natalie, a decision *not* to talk about the illness does not constitute a deliberate attempt to be slyly secretive about the illness. Instead, it simply signifies the sufferer's desperate attempt to protect the Self from the deeply hurtful reaction of others. In turn this approach heightens the sufferer's sense of isolation (cf. Crook 1982: 73; Strauss & Glaser 1975: 54-57; Ware 1999: 316-317).

This isolation signified the very essence of each sufferer's tribulation...

... die isolasie dink ek het... het rêrig my heeltemal ondergekry, dit is iets waaraan ek glad nie gewoond was nie... (Natalie)

But why does the sufferer find it so difficult to bear? If it is such an arduous task to build and maintain friendships, is there then no relief in not having friendships to maintain? For the participants in this study "not having friendships to maintain" brought no relief for, despite their illness they *are* still very much human. Natalie explained:

... ai, ek is dan lyk my maar ook 'n mens... ja, ek wil vriende hê en ek wil aanv..aanvaar word... Ja, daar word altyd mos gesê jy moet jou nie soveel steur aan... dis mos nou net 'n eksterne ding, maar... nee, ek dink nie so nie, ek dink dit... dit is alles deel van jou emosionele maaksel, wie jy is... is jou vriendekring, die mense waarmee jy omgaan, so... Dis een van die kwessies, dink ek... mmm... wat vir my dit baie moeilik gemaak het, want natuurlik wil ek ook mos aanvaar word, natuurlik wil ek 'n vriendekring hê...

Natalie is an ME sufferer *and* she is a human being. Thus, in the midst of her suffering, she longs to share the harmony of acceptance and friendship with others. Instead, she now experiences the pinnacle of isolation - loneliness:

...die waarheid is, ek het miskien nie meer so baie vriende oor nie... dis vir my baie moeilik, ek is eintlik baie alleen... ja, dis... vriendskapsgewys is ek baie alleen... Ek weet nie, ek het net so... dit was net so 'n kluisenaarsbestaan vir so lank dat ek so... jy weet... So, dit is... ja, ek is alleen, dis 'n... dis 'n feit. Ja, ek voel alleen... dis simpel, maar ja...ek voel baie alleen.

Natalie's words speak for all participants. It is an experience of stark aloneness, of being forced into solitude.

Thus, the participants responded to tribulation; they changed. They changed because of ME. They changed because of the stubborn ignorance encountered in others. As a result, they are now caught in the midst of a conflict raging between their desperate need for self-protection and their inmost longing for the intimacy of friendship. In this conflict the ME sufferer is

vulnerable – overwhelmed by the difficulties they face that emerge from both the direct consequences of living with a chronic illness as well as the impact of that illness on their ability to maintain a sense of normalcy (cf. Atkin & Ahmad 2000: 509). This conflict, left unresolved, will potentially thwart the ME sufferer's avid desire to live life as normally as possible. For, as Ware (1999: 317) suggests, the more intense the experience of isolation, the more difficult it becomes to connect to the outside world. Thus, already marginalized and dealing just with the illness itself, people with ME may find they have lost the sense of a world shared with healthy people. When this happens, increased social distance seems inevitable.

To cope…

Natalie unveiled an eternal longing:

… dit sou *soveel makliker* gewees het as mense 'n ander… uitkyk daaroor gehad het… vir 'n mens self…

At this moment Natalie's "if only" longing is not part of the reality of ME. But, if 'if only' is merely a wishful fantasy, how does the ME sufferer cope?

To cope within the realm of friendship is, as each participant discovered, often extremely difficult. See how this is clearly revealed in Natalie's description:

… ek het nou iemand gehad by die Technikon wat my gedurig deur… dis asof sy my uitgesoek het elke dag om vir my te sê ek moet 'n meer positiewe ingesteldheid hê en ek moet meer geloof hê en ek moet… En ek het later, omdat ek *nie geweet het* hoe om vir haar… te… te laat *insig* kry en… en te laat verstaan dat ek al daai dinge probeer en dat dit my *nie* gaan help as sy my raad gee elke dag nie, het ek my begin distansieer van haar, jy sien, ek het haar begin vermy en so aan… Dis *al* wat ek kon doen… dit kom maar net terug na my toe, omdat ek nie weet *hoe* om te… te reageer daarop nie… Sien, dit raak net later *so moeilik*. Nou, ek… *liewe aarde, ek weet nie*, jy weet, ek het soveel aande huis toe gekom en… en ek het besef sy is besig om die oorhand oor my te kry… *maar ek weet net nie hoe om dit te hanteer nie*.

Natalie was tortured by the anguish of "not knowing" how to respond:

Ek het nog nie 'n antwoord gekry oor hoe ek moet optree teenoor vriende nie, wat sal die oplossing wees nie… mmm… want ek het al alles probeer, ek het al probeer om eerlik en openlik met hulle te wees of ek het al probeer om dit te ignoreer… Albei kante toe werk dit nie… my een vriendin sê vir my ek maak nie oop teenoor haar nie, wat vir haar 'n klap in die gesig is, die ander vriendin sê sy wil niks van my weet nie… mmm… ek moet net… ek is net haar vriendin, sy stel nie belang om dieper te kyk nie… Nou watter

kant toe gaan jy nou, want as ek iets sê dan onstel ek die een en as ek nie iets sê nie ontstel ek die ander een... Dis baie moeilik...

The distress is obvious. The solution is not.

Still, the participants did find the "unobvious" solution. They discovered choice. Denise described this discovery as follows:

... dit is... 'n wilsbesluit, want gewoonlik wil ek alles doen, en jy dink as jy dit nou nie gaan doen nie dan... jy weet, wat gaan hulle nou dink en wat gaan hulle nou sê en al daai dinge... Maar ek het toe nou net vrede gemaak daarmee en jy kom op 'n punt waar jy nie omgee wat mense van jou dink nie, jy moet... *jy* moet daarmee saam leef...

In choice, Denise found a way to deal with the reactions of others to her and her illness. She discovered that she could deliberately choose how to endure and respond to their reactions. She discovered that in the power of choice lay the power to govern her own experience.

Helen's account offers further elucidation of this discovery:

One large turning point in my learning to cope with ME, was the day I realised that I did not have to subject myself to the negative responses I received from others... and could actively avoid encounters with those individuals that invariably left me feeling misunderstood and drained from energy... It left me feeling more empowered... and less the victim of others' views and lack of understanding...

Helen recognised that although ME sufferers are almost inevitably bound to confront negative reactions from others, including from friends, they have the power to protect themselves from such reactions. Armed with this realisation, Helen firmly resolved not to expose herself any longer to the negative comments and contributions of others. Helen too discovered the power to guide and command her own experience.

Thus, the discovery of choice empowered these participants. More specifically, it empowered the participants to control their experience amid friends through the choice to discriminate, to adjust and to accept:

Firstly, the ability to choose empowers one to discriminate. Cheryl explains:

.. you are the only person I've talked to in depth... in depth on this subject... I am careful who I... I talk to... more than just... superficially. There are certain people who you know really want to know. And the other people... when they say, 'how are you', *desperately* want you just to say, 'fine'. You have to learn to find out which ones are which! I... I think I've... I've learned pretty much which ones are our friends by now.

It is ultimately Cheryl's choice exactly what she will reveal about the illness, and to whom. Through this ability to discriminate she finds the power to determine whether or not her ill status will enter into or even impose upon her interaction with friends. Ware (1992: 353) identified a similar tendency in her work with ME sufferers. Strauss and Glaser (1975: 60-61) identify this approach as a "normalizing tactic" through which chronically ill persons work hard to keep their poise. It is a tactic that Atkin and Ahmad (2000: 509) also identified among their participants who suffer from thalassaemia major. Through the power to choose and the resultant power to discriminate Cheryl, like other ill persons, do their best to maintain control of the nature and content of their interaction with friends.

Secondly, through the discovery of choice the ill person is ordained with the power to adjust. Cheryl again illustrated the reward gained through the power to adjust within the context of friendship:

... as far as... good friends are concerned I cannot function socially as I used to. I was well known for entertaining and good cooking... now all we manage is a few bits of salad sliced by one of the children, bread rolls and some braaied meat... after 1994 we only ever braaied for friends... I've never cooked a lovely meal for friends since then... very sad... But braaiing and chopping up tomatoes and spreading rolls can at least bring friends together even if not haute cuisine!

Thus, instead of choosing to avoid friends while seriously ill, Cheryl chose to adjust... to invite fewer friends at a time, to make meals simpler, to employ the rest of the family in the preparation of dishes, to accept help when offered. Perhaps this sounds mundane or even insignificant, but it is not. Adjustments such as those described in Cheryl's account allow the chronically ill person to sustain invaluable friendships despite the odds.

Lastly, the power of choice offers the ill person the opportunity to accept. This acceptance follows a two-step process which, firstly, requires an acceptance of the stubborn nature of ignorance among friends. Helen explained:

I tried extremely hard to accept that I would never be able to convey to people the real isolation, loneliness and depression one feels coping with an illness that has no guaranteed time limit and that draws a halt to most aspects of your life. In order to cope, I began to spend less energy on trying to convince others of what I was feeling and concluded that most people will never understand such an illness unless they have the misfortune of suffering themselves... or witnessing a loved one suffer...

There is no road around this obstacle called ignorance. It is there, and it is stubborn. Yet, instead of responding with tiresome resistance, the ill person can choose to acknowledge its presence in the very midst of friendships.

The choice that makes allowances for the obstinate nature of ignorance empowers the ill person to accept friends. It is not an acceptance of friends despite of their ignorance, but it is rather an acceptance of friends because they *are* friends. Cheryl's account illustrates this choice perfectly:

... we've got a... couple of groups of friends like that... who we cherish, because we have had them for many, many years... from before we got married, they were friends... and we are not prepared to loose them on the grounds of the fact that they can't come to terms with the illness they don't understand... and we haven't tried to force it on any of our friends...

Hence, in accordance with the choices she had made, Cheryl was able to observe:

I... I've come to accept in... in my friends that are too precious to loose, I've come to accept that they... can't accept it, so I just accept them...

For Cheryl, embracing the power to accept allowed her to prevent her status of being ill and the lack of understanding surrounding it from destroying the usual ("normal") character of her interaction with cherished friends... precisely because they *are* such cherished friends.

Taken together, these strategies point to a recognition among ME sufferers that in a world where their condition already precludes full social integration, they should ideally avoid doing anything that would call further attention to their impairments if they wish to preserve whatever degree of social connectedness they still possess (Ware 1999: 316). By doing so through personal choice, they are now in charge of the very essence of their social interaction. Such interaction – and the friendships that may depend on it – is now fully under personal control.

However, as Ware (1999: 316) points out, this approach to social integration tends to result in a kind of "silencing" of talk about illness. Participants, even more than the most of us, cannot admit to feeling less than "fine", cannot make reference to illness-related issues or activities, cannot discuss their limitations. If they do, they risk compounding their social isolation through abandonment or outright rejection by others. If they do, they forsake the dream of living their lives as normally as possible. But if they do not, they may find they have preserved outward social ties at the expense of their inner authenticity. Paradoxically, then, those very attempts at ensuring connectedness to the social world may lead to alienation from the Self.

Conclusion

ME sufferers pursue a vision of normal life, despite the symptoms, limitations and adjustments caused by their illness. A fundamental element of this vision is the friendships which sufferers forge. The discussion above has revealed that while some friendships stand firm in the presence of ME, others appear to be frail and crumble dismally in the face of this illness. One cannot but wonder what determines the stability, the sustainability, of these friendships?

At first glance, it appears as though the answer to this question lies in the forces which govern the fundamental strength of the ME sufferer's relationship with friends. In many situations the strength of friendships falters under the cruel influence of ignorance. Such cruelty induces the sufferer to change. It prompts a newfound awareness of the need to protect the Self, even against friends. It builds and re-builds a wall of isolation. Thus, the forces of cruelty create a lonely void in which many friendships simply dissolve. Still, in other contexts, the vivacity of the ME sufferer's friendships is sustained through unwavering, unqualified kindness. It is a caring kindness which is independent of any understanding of ME. It is a caring kindness which allows the sufferer the freedom to be and express the Self, not only on the road to wellness, but also in the pursuit of the ultimate vision of "normal life". It is in the forces of kindness that friendships find the spirit to survive.

Is it then the forces of cruelty and kindness alone which test the strength of ME sufferers' friendships?

I argue that that is not the whole truth. The forces of cruelty and kindness *are* most certainly at work, but to accept their influence as a conclusive explanation would deliver sufferers helplessly into the hands of forces seemingly beyond their own control. And this is not the case. ME sufferers are not the victims of their circumstances; they are not the victims of their illness. They share responsibility for the vigour and vitality of their friendships. They *have* a contribution to offer and a choice to make. Indeed, through choice sufferers have the power to redesign, to shape, to guide both the content and nature of their friendships. While some friendships may always resist the power of choice, others will endure and prosper, *because* the sufferer made a choice.

Thus, it is the sovereign power of personal choice which keeps the ME sufferer's faith in friendship alive and, hence, makes the earnest aspiration "to live as normally as possible" attainable.

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Chapter 14

The media: Teacher or false prophet?

Cassell (1991: 52-53) reminds us that "even though suffering is an essentially private matter, the notion of privacy supposes a public world". Indeed, the public world is the world where life is lived. It is the world where ME exists. It is the world where ME sufferers tread. It is the world where much suffering occurs.

So far we have established that in this public world, ME sufferers interact with physicians, family and friends: they meet, they join, they concur, they communicate, they participate, they associate, they relate, they challenge, they clash, they collide, they contradict, they confront, they dispute, they resist, they protest. But their circle of interaction extends ever outwards, beyond these personal bonds, and they meet society at large.

This section will be devoted to their encounters with the primary representative and interpreter of society at large: the media. Wessely et al. (1998: 312-317) show that the media played an important and complex role in the social history of ME and that it is therefore necessary to scrutinise very carefully the media's contribution in shaping the public perception of ME and hence the personal experiences of ME sufferers. The participants too support such a scrutiny. Natalie spoke for all participants when she stated:

... die media... man, hulle speel mos nou 'n *baie* groot rol... want wat hulle daar gaan uitdra is... dis wat die mense gaan *glo*... So hulle... het so baie... *almal*... *almal* wat enigsins weet daarvan... hoe... *hoe* kom hulle aan daai inligting... *of* hulle ken iemand wat dit het *of* hulle het daarvan iets gelees in die media.

Indeed, the media, both locally and abroad, has been inundated with reports concerning ME and the plight of those who suffer from it. MacLean and Wessely (1994: 776) agree that "during the past decade attention given to the chronic fatigue syndrome by the professional and popular press has risen enormously producing a media epidemic". Hence, in their journey through the public world, the participants in this study were inevitably exposed to the media's version of their illness.

Nurturing wellness

Participants' accounts reveal that, on their road to wellness, media coverage of ME has served a very important purpose by giving widespread publicity to the illness. Cheryl noted:

The media has done... a... a favour to people with ME, to a certain extent, by publicising it...

Indeed, the extensive media coverage of ME facilitated the broad dissemination of an awareness of and interest in ME.

For sufferers this may be of vital importance, as many of those with whom they interact in the public world will only know ME by the reports they have come across in the popular media. Note, for instance, how Cheryl's reasoning behind her use of the term "yuppie flu" illustrates this point:

I still use that term when I'm speaking to somebody who genuinely seems interested, but obviously is not going to have a clue until you mention 'yuppie flu'. So, I still use that term to help people out when they are trying to understand what's wrong with me... and generally for nurses. They've read more in the You magazine than they will in... in any textbook, that's for sure...

When people genuinely try to understand or are in a position to help the ME sufferer, use of the widely publicised term "yuppie flu" represents the first easy manoeuvre towards creating greater insight into the sufferer's situation.

Furthermore, because there is a tendency within the media "to promote polarization and division whenever considering unexplained symptoms and syndromes, areas which by their nature are grey and uncertain" (Wessely et al. 1998: 317-318), discussion and debate will follow when reports on ME appear. Cheryl recognised the potential value of this tendency:

... I can't *honestly* say there's been a *single* article... in *normal* media, I don't mean a proper, well-researched book... mmm... no, not ordinary journalists, they haven't done any good. The best I can say is that they've created debate... which is not been... mmm... has not been without its merit.

Thus, through coverage of ME, be it of whatever nature, the media promotes controversy and contention, dispute and deliberation. It offers a vital forum in which different views, often conflicting and contradicting, may be heard and weighed. It allows each beholder to reach his or her own verdict concerning the substance of ME.

A further important result which follows from the widespread coverage enjoyed by ME is a growing awareness among sufferers, such as the participants in this study, that they are not

alone, that there are others who share a plight similar as their own. Denise gave expression to this awareness:

... ek dink met die media... het jy... het jy die ondersteuning beleef van 'hier is nog mense wat voel soos wat jy voel'...

What comfort to know: "I'm not alone". The discovery that they are not alone inspired a growing sense of community with other ME sufferers among the participants. This is evident in Denise's words:

En... mmm... om te weet daar is nog ander mense wat... wat min of meer deur dieselfde gaan as waardeur jy gaan... Dit het jou half in kontak gebring met... met ander mense...

For sufferers such as Denise, the certain knowing that there are "others" with whom they share such a central part of their live gives rise to a sense of security, coherence and mutual support. The emergence of such a sense of group identity is, as Wessely et al. (1998: 272) maintain, strongly facilitated through media coverage of ME. According to these authors, it is especially the language of such coverage which prompts impassioned group identification. In substantiation of this contention they refer to an editorial in a patient's magazine entitled, "Belief in Ourselves" which commented that, "We are standard bearers... We know that somehow, somewhere, out there, a mistake has been made. We know we are in the right... Every sufferer's experience helps us bear witness to the truth... One day we shall prevail" (in Wessely et al. 1998: 272). It would indeed be difficult to ignore the effect of such passionate rhetoric and conviction. Reports of this nature must undeniably contribute towards an awareness of an "us", of a group to which the ME sufferer belongs.

The media's chronicle of the stories of specific ME sufferers does not only inspire a strong sense of community, but may also lead other sufferers to feel more empowered. When they read or hear what other sufferers have accomplished, it provides assurance, hope, and expectancy. Cheryl observed:

Even Yankelowitz and his story has got so many people in such a state of running around the country after lawyers... in the hope that they will get something from Old Mutual. So, somewhere somebody might have been helped... to stand up for themselves or to understand the illness a bit better...

The "Yankelowitz story" to which Cheryl refers concerns a very recent court case in which Mr. Leon Yankelowitz, a ME sufferer from Cape Town, took Old Mutual to court over its refusal to pay out a disability policy for ME. In August 1999, three Cape High Court judges ruled against the insurance giant (Coetzee, 1999: 138-139; Mokwena 1999: 1).

The court's decision made newspaper headlines and, in the Cape Times, even the front page where it was aptly titled, "Yuppie flu: Landmark ruling a victory for sufferers". It was widely heralded as "binding on all disability claims by yuppie flu sufferers" (Mokwena 1991: 1). It was a ruling that would "bring relief to people whose claims were previously treated with scorn" (Mokwena 1991: 1). It was declared "a precedent setting judgement", one that would certainly 'pave the way for other long term sufferers who are unable to work and can be considered permanently disabled' (Whitaker 1999: 3). This case indeed set a precedent.

Through the media coverage enjoyed by this single case many ME sufferers such as Cheryl became aware that they could now, for the first time, claim disability benefits on the grounds of their disabling condition. Hence, through their newfound knowledge, they were empowered to act in their own best interests.

Thus, as the participants in this study experience, the widespread publicity enjoyed by ME facilitates a greater awareness of and deliberation on the substance of their illness within the public world. For them, the media-inspired interest in ME often provides a valuable background when communicating their situation to those who want or need to understand more. In addition, the media coverage of ME provides the certain knowledge that there are others who share their plight, with whom they enjoy a sense of community, and from whom they can learn much. In this knowledge the participants found the security, encouragement and expectancy to act on their own behalf... and hence to advance on the road to wellness.

Cruel encounters

The essence of cruelty is the expression "yuppie flu":

... you know, 'yuppie flu' did us *a lot* of harm. Everyone with ME was now branded... (Cheryl)

For all the participants the most negative aspect of media coverage of ME was the use of the term "yuppie flu".

Consider Denise's observation:

Mmm... ek weet daar was artikels in die Huisgenoot en ander tydskrifte en sulke dinge wat die sogenaamde *'yuppie griep'* bespreek het en sulke dinge... en ek dink dit het... meer *skade* gedoen rêrig as goed... want... toe het almal begin dink, joe, as jy moeg is dan het jy 'yuppie griep'... Dit was hierdie term wat almal op 'n Donderdag-middag begin uitpak het by die werk... jy weet...

For ME sufferers such as Denise the label "yuppie flu" is loathsome and offensive. For journalists it provides an eye-catching headline and gives the subject a wider, if inaccurate, social context (MacLean and Wessely 1994: 776-777). In short, it sells newspapers.

It appears therefore as if media coverage of ME, and specifically the use of the term "yuppie flu", was chiefly directed at sensation. The facts were not important – or at least not *as* important as the story. Denise recognised this bias in the press:

... ek dink baie van die media... dit het gegaan oor sensasie en nie... nie rêrig oor die *feite* nie... die kriteria wat hulle daar sit vir ME kan elke derde mens omtrent mee kwalifiseer... mmm... en van daai goed het 'n mens se hare rêrig laat reg-op staan... *Ongelukkig* was die minder goeie artikels, dink ek, in tydskrifte wat groter publisiteit geniet...

The pursuit of sensation unfortunately justified the bias. This tendency is supported by the findings of MacLean and Wessely's (1994: 776-777) research on newspaper coverage of ME. These authors discovered that all journalists that they interviewed "agreed that their primary criterion for covering this or any other topic was 'will it make a story?' Hence, although the journalists were often aware of other research papers, they did not cover them because they were not newsworthy".

"Newsworthiness" – sensation – the ability to sell – was thus the key credential of a "good story". What classified a ME report as a "good story" was, as MacLean and Wessely learned, not only the eye-catching "yuppie flu" headline or the broad social context to which it apparently applied, but also the utter controversy in which the illness is immersed. According to journalists interviewed by MacLean and Wessely (1994: 777) "the highly charged medical, social, and political atmosphere surrounding the subject made it good copy".

The participants experienced that when sensation was the main consideration in a news story, a lack of facts and general misinformation prevailed. Cheryl disclosed:

... it has done, generally speaking, it's done more a disfavour, *really*, because they've trivialised the illness... and... people then do believe that, you know.

MacLean and Wessely's (1994: 777) research revealed that the trivialisation of ME was often most noticeable in the health pages of the women's press. These pages often follow a coherent theme – "that of empowerment in health and lifestyle. They promote the philosophy that 'total health' is possible if you follow the appropriate diet, take the appropriate nutritional supplement, or adopt the appropriate lifestyle. The unsubstantiated claims concerning the

efficacy of changes in nutrition, diet, and lifestyle in the chronic fatigue syndrome fit in with this philosophy". Such claims do not only provide misinformation and false hope, but also create an illusion that the ME sufferer's state of health is personally completely controllable. In other words, if the sufferer does not recover it can be ascribed to his or her own doing, or lack of doing. This approach is intrinsically cruel, because it belittles the true complexity of health and illness and places the blame for suffering squarely on the shoulders of the sufferer.

Distortion, misinformation and trivialisation often go hand in hand. Cheryl recalled:

... I don't actually even believe that what we read is necessarily that person's *actual* experience... because I can get half way through an article on... 'my life changed'... you know, 'an x number of years ago when suddenly I couldn't get out of bed the next morning'. And I can get half way through the article and suddenly it is *unrecognisable*. And yet half way down you *knew* that that person had ME, it was *so* clear. And then the... the journalist gets lost somewhere down the... along the way... I don't know whether folk are educated even... enough to even recognise those sort of anomalies.

Natalie also pointed out how much ME is distorted in the media:

Verder word ME dikwels in die verkeerde lig gestel... deur die media. Die media sê soms dinge soos dat dit slegs A-persoonlikhede is wat daaraan ly, dat dit oorywerige, ambisieuse mense is wat hulleself uitbrand...

Media coverage of this nature severely distorts the true character of the illness and of the suffering which accompanies it. In fact, it simply adds further suffering. This notion is supported by Barsky and Borus (1999: 910-911) who show that the media often uses hyperbole and uncritical reporting to portray complex and often misunderstood syndromes such as ME. They state that "preliminary data, tentative findings, and the personal accounts of individual sufferers are reported as conclusive medical evidence". Through sheer sensationalism and alarmism the media may indeed serve to compound and intensify the ill person's subjective experience of the illness.

A very important and, for the participants, a very prominent feature of misinformation and distortion of ME in the media is the almost absurd fanfare and publicity surrounding the discovery of so-called 'miracle cures' – by the dozens! Natalie said:

Nog 'n erger onkunde wat gesaai word is hierdie sogenaamde 'nuwe genesings' – wat ek nou in hoofletters wil benadruk – dit word dikwels bemark in die vorm van 'n nuwe middel of 'n nuwe dokter...

The sheer detestation in Natalie's words speaks for itself. So too does the annoyance in Cheryl's statement:

... we don't need silly reports about 'yuppie flu' and miracle cures and... and then you spend... you spend your entire salary on Moducare and you still don't get better, you know...

Also, consider what Denise had to say:

... ek dink ook spesifiek... ek dink nou aan 'n ander artikel wat in die koerant was van... onlangs van... hierdie wonderlike... mmm... deurbraak... in terme van om ME te behandel... en... dit is... dit is 'n klomp *nonsens*... So dan... dan breek dit ME se beeld verder af in plaas van om dit rêrig op te bou. So, ek dink die media... sit... sit vir my... die pot redelik mis wat ME aanbetref... ongelukkig...

The media is indeed in error. Moreover, through their sensational blundering they again and again exacerbate the ill person's suffering. They promise hope and recovery, and leave the sufferer to pay the price of disillusionment. For ME sufferers the media's eager exaltation of each new "miracle cure" represents a bitter cup filled to the brim with false hope and the guarantee of bankruptcy.

In response...

In their response to the media's public portrayal of their illness and of their private suffering, participants followed a barren road leading from frustration to apathy.

Cheryl expressed the intense frustration she experienced in the face of harmful reporting:

... they (the media)... know *so little*... that... I suppose in... in my own menial strength I become enormously frustrated with them.

Denise supported this sentiment:

... ek dink met die media... het jy weer 'n frustrasie beleef van 'hierdie is nonsens'...

After much exposure to hurtful reporting, the participants' experience of frustration turned into disillusionment. Natalie explains the new perspective she developed:

... ek het nou 'n heel ander sy van die media gesien, sien, ek... ek het so baie gelees oor 'wonder-kuur', jy weet... en dan weet ek maar dis nie waar nie. So, ek het nou 'n heeltemal 'n ander verhouding met die media as wat ek... wat ek miskien sou hê. En dis baie goed, ek is baie bly daaroor... andersins sou ek net toe-oë deur die lewe gegaan het! Almal... baie mense... mmm... joe, 'n mens... mens is darem *baie* verkeerd om... om te glo in die media...

Natalie's repeated exposure to ignorant and distorted reporting transformed her perspective on the very nature and conduct of journalism. She discovered that the creations manufactured by

the media is not to be taken at face value because in such creations truth and untruth are often intimately intermingled, all for the sake of "a good story".

For some of the participants this disillusionment often led to outright avoidance. Natalie explained:

... ek het... gelees... so hier en daar... artikels gelees van mense wat daardeur gegaan het... dit was vir my maar... dit was net altyd vir my... *nie* aangenaam gewees nie... Weet jy, dit het my baie keer ontstel... dit raak 'n mens nog baie... daarom lees ek glad nie... ek weet nie of dit 'n manier is om myself te beskerm nie, maar ek distansieer my redelik baie...

In order to protect themselves against further wounds inflicted by slanted sensationalism and distortion, ME sufferers such as Natalie deliberately shun the media.

As ME sufferers become disillusioned and start avoiding exposure to the media, they are inclined to become increasingly unresponsive to the iniquities committed by the media and eventually to reach a stage where their energy to protest against the distortions dies away. Cheryl explains:

I'm *not* a ME lobbyist anymore, so I don't ever respond... I might have in the beginning... I can't remember... But... mmm... *now* I... I feel... *now* my reaction to anyone who is so ignorant, as the press could be and some of them *are*, would be that... I'm too tired to educate them...

One detects an apathy, even a dispirited surrender in Cheryl's words: "Why bother, they certainly won't listen; they're obviously not interested in the facts" – the sad results of inaccurate and sensational journalism.

Thus, in response to the media's mistreatment of their illness and the blatant ignorance which was put on public display, the participants in this study first experienced a sense of frustration which grew into disillusionment as they repeatedly recognised how easily the media mixed truth and untruth. Finally, the thought of protest dwindled into detachment and indifference, for they now had to start protecting themselves against the distortions and falsehoods put out by the media.

To cope...

The participants often found it difficult to cope, or to know how to cope, with the media's distorted presentation of their illness. As thankful as participants were for the greater public

awareness and debate that was stimulated by sound media coverage of ME, as bewildered were they by frivolous coverage.

To comprehend what exactly ME sufferers confront in the media, consider the following distressing example. It is an extract entitled "Tekens van yuppiegriep" from a regular health column which recently appeared in a well-known and widely read Afrikaans Sunday newspaper (Suster Wagner 2000: 5):

Liewe Suster Wagner:

Ek is 26 en het verneem dat ek yuppiegriep het. Of altans, dis is hoe 'n vriend my diagnoseer. Ek sal seker die een of ander tyd dokter toe moet gaan, maar wat sê ek vir die man? My simptome is gedurige moegheid en 'n verkoue wat kom en gaan. Kan u meer inligting omtrent hierdie siekte pos? Ek sal graag meer tekens wil ken voordat ek dokter toe gaan.

Antwoord: Jy verwys na 'n sindroom wat dokters al lank laat kopkrap. Dit is in die laat jare vyftig deur 'n dokter van Pinelands aangeteken as 'n siekte, maar tot nog toe kon geen laboratoriumtoets enige verband vind tussen die sindroom en 'n virusteenwoordigheid nie. Die feit dat mense soms koorsig is en verkoues kry, is deel van die resultaat van moegheid en dat die ou gestel dan bietjie af is. Die beste behandeling is bedrus. Die feite wys dat die meeste mense met die sindroom mense is wat laat werk en baie vlytig is totdat hulle naderhand begin sukkel. Dit kom veral by vooruitstrewende jong mans voor. Vandaar die naam yuppiegriep. Al wat jy vir jou dokter moet se, is hoe jy voel en waarom jy dink jy het die sindroom. Hy sal jou goeie raad gee.

Suster Wagner's response to the questioner's inquiries shows outright ignorance. The little information that is offered is at best questionable and at worst completely wrong. ME does not merely entail a fever and a cold, or a body that feels a bit on the down side. ME is not treated by complete bed rest. ME is not predominant among men. ME is not the same as "burn-out" due to over-eager over-exertion. What Suster Wagner imparted did not constitute "die feite" about ME, nor did it offer any useful help to the questioner. She did, however, succeed in showing a dreadful ignorance, in perpetuating the many misconceptions surrounding ME, and in adding to ME sufferers' concern about appalling media coverage.

Suster Wagner's reply is but one example of ME sufferers' recurrent "difficult-to-cope-with" exposures to the media. Natalie peaks for many ME sufferers when she says:

Hierdie soort sensasie-media en mense se onkunde beïnvloed die reaksies teenoor jou as lyer en dit beïnvloed jou *eie* reaksies teenoor jouself.

Instances such as Suster Wagner's portrayal of ME are difficult to cope with exactly because they influence how others think about ME and, hence, how people respond to those who suffer from ME. Moreover, such instances make it even more difficult to cope with the illness because they influence the sufferers' *own* perspective about the illness and thus, how they respond to the Self.

In order to cope and to avoid complete bewilderment ME sufferers need to make sense of these instances of ignorance in the media and to reach some understanding of the media's portrayal of their illness. Cheryl offered a description of her attempts to do just that:

I don't know a media person who knows more than I do about it for sure. There's no one who... bothers... but for what would they bother to study it for? I mean when Kosovo and... and... mmm... all these...these... I mean, Chechnya and these things that are happening all around the world are occupying journalists of the highest calibre... *why* one earth should they investigate ME, *why* should they even *try* and get to the bottom of ME? I mean, there's absolutely *no* good reason for it. So, I don't blame the journalists...

She added:

... I can't actually see *why* I, as a journalist, would go out on limb for ME. Let's be frank, I mean, what is in there for them? They are not going to win the Pulitzer Prize of the year for a report on ME. They are not going to win *anything*, except an awful lot of controversy next time they visit their own GP... or if they... heaven forbid, think they've got ME. They'll forever be thought of... that they just associate with these people.

Cheryl rationalised the situation and developed an understanding that allowed her to make sense of journalists' lackadaisical approach and attitude towards ME. This helped her to comprehend and even accept journalists' evident lack of interest to understand the illness and to reach her own personal understanding of the situation.

Thus, because of the ignorance about ME that they found in the media, the participants were challenged to discover a way to cope with journalists' depiction of their illness. It became even more vital to do so when they realised how many people – including ME sufferers themselves – are influenced by what the media prints. The participants met the challenge and they developed a personal understanding that allow them to acknowledge, comprehend and even accept the media's presentation of ME.

Conclusion

The media – the primary representative and interpreter of society at large – puts private suffering on public display. It presents to the public world an image of ME and the suffering which takes place behind closed doors. The participants found that this image has two faces.

The first face can be described as kindly benign as it smiles down on ME sufferers. It creates a public awareness of their illness, it facilitates interaction with the world outside their illness and it stimulates debate about their illness. It offers the sufferer personal justification because it shows that the illness does indeed exist, and it offers a break-out from isolation because it shows that there are other sufferers too. This face of the media lightens the ill person's experience of suffering. The second face is a cruel one. This is the face of sensationalistic journalism that is more intent on selling a "good" (albeit even false) story than creating understanding and spreading enlightenment. This face unquestionably adds to the ME sufferer's burden of suffering.

The double-faced image of ME presented by the media prompts ME sufferers such as the participants in this study to review their beliefs and ideas about the media, its conduct and its creations. They have learned to quickly distinguish the combination of truth and untruth, and they have learned to understand that the sensationalism, the misinformation and even the blatant ignorance are all part of the publicity package. And, after all, they understand that the media is certainly not obliged to ease anyone's suffering.

The media's double-faced approach to ME ultimately becomes an expression of the very natural conflict situation that exists between the sick person and the public world. It is a conflict that revolves around *different* interests, motivations, and ideals. It is a conflict that again sharply highlights the undeniable fact that ME sufferers do not exist by themselves and unto themselves, but that they are very much a part of society at large where life *and* suffering are lived.

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Chapter 15

Society at large... at last

The ME sufferer's circle of interaction expands ever outwards, until it reaches the furthest frontier of experience: society at large. This is the world where social forces constantly influence and shape the ME sufferer's subjective experience of illness. It is a very real and immediate world, known not only through its primary representative, the media, but also more directly and more personally through person-to-person contact. I now turn to the participants' experiences of such contact in order to explore and illuminate their encounters with the social dynamism that ultimately defines their human reality.

Nurturing wellness

On the road to wellness, the participants in this study experienced extraordinary expressions of kindness within society. Cheryl ardently exclaimed:

... there was... there was incidences of kindness that were unprecedented, I mean, you can't imagine how wonderful people were...

The participants often defined kindness simply as the absence of disbelief. Consider what Denise says:

Ek het griep gekry of 'n... 'n lugweg-infeksie... ek moes toe daarna vir sewe weke lê, dit het my totaal... van my voete afgehad... Dit is 'n moeilike situasie, want jy begin by 'n nuwe werk en almal vra vrae, maar... jy beleef... ek het meer ondersteuning beleef as wat ek skeptisisme beleef het... waarvoor ek dankbaar was...

Denise equates gestures of kindness within society with support without any scepticism, doubt or disbelief. Thus, kindness is to have others accept and believe one's experiences, even when they may not understand or have insight into the illness.

At other times, kindness in society was described as the willingness to offer practical help when needed. Natalie offered the following testimony of such kindness in society:

... ek het al baie ondersteuning gehad van mense, prakties-gesproke, as ek iets moes doen of so... Mmm... ek sou mis... ek gaan mos nou nie in detail in nie, maar ek sou vir hulle, byvoorbeeld, sê...

mmm... ek is siek of hulle vir my sal help met hierdie of daardie of so... en dan help hulle my. Dis wonderlik en ek is baie dankbaar daarvoor...

This willingness of people to make an effort makes an incredible difference to ME sufferers because it helps them to achieve what would have been impossible without assistance.

The participants say that kindness in society also lay in the friendly advice offered spontaneously by others. Natalie recalled:

Ek het 'n wonderlike, wonderlike lektor gehad! Hy't vir my niks prakties gedoen nie, maar hy het vir my daai ondersteuning gegee... psigies... Ons sal voor die tekenbord staan dan sal hy vir my sê, maar, ek's te styf, my liggaamstyl is baie styf, nou ek weet hoekom, as gevolg van pyn en moeg en altyd... jy weet, is ek ingetrek, ek's glad nie meer los en oop en... soos ek was nie, maar ek was nooit bewus daarvan nie, maar hy sou dit vir my sê, hy sou vir my sê, 'I don't know why, but you... you're co... cranked up all together, you know, open your arms'... dan sal ek nou eers baie kwaad wees, jy weet, wie is hierdie man nou... (lag). Maar dit het my baie gehelp, dit het my rêrig gehelp, want ek dink ek het baie dinge oor myself geleer en ek het gesien hoe ek lyk wat ek nie voorheen gesien het nie... so dit was 'n goeie ervaring...

For Natalie, the constructive advice offered by her lecturer was essential for personal and professional progress. It presented the opportunity to learn more about herself, to adjust and to grow, despite the odds.

However, the participants also reveal that they did not simply wait for instances of kindness to happen, but that they actively sought out nurturing support. They deliberately avoided or tried to avoid unresponsive or critical encounters and moved to more sympathetic social spheres (cf. Strauss & Glaser 1975: 54-55). Such sympathetic spheres often involved interaction with fellow ME sufferers. Natalie described her experience in this regard:

Ek het nog heel..heelwat kontak met ander ME-lyers... Dit is... miskien... mmm... dis maar wat ek my vriende kan noem, omdat... ons praat dieselfde taal, jy sien... hulle verwyt jou nooit... of sê ooit vir jou... mmm... lig jou ken op en staar die wêreld in die gesig nie... Dit het my goed laat voel om te weet... mmm... jy is deel van... van 'n groep mense daar buite wat... wat weet, wat *verstaan*... en dat jy nie die enigste een is nie... dis *ongelooflik* belangrik... En... die insig... dis net... daar's goed wat hulle *heeltemal* verstaan, hulle verstaan... hulle verstaan al die *praktiese* probleme... Ons het, byvoorbeeld, in die afgelope elf jaar nog nie een keer met vakansie gegaan nie... dit klink baie eienaardig, maar dit was net tot dusver 'n baie moeilike ding om aan te pak... En... om dit vir so iemand te sê... hulle verstaan dit 100%, want hulle is in... *baie* van hulle is in daardie posisie... Dis half 'n verstaan wat 'n mens nie hoef uit te spreek nie, dis net 'n band wat jy het... wat... wat help.

Interaction with fellow ME sufferers offered Natalie the security of knowing that there are others who share similar problems and difficulties. It also offered a sympathetic context in which Natalie was able to openly express her experience of ME without fear of judgement or rejection. It was indeed a haven of nurturing support.

Natalie elaborated:

... dis vir my goed om nou en dan... kontak te maak en... ja, ek reken as 'n mens terugvalle het dan is dit die beste eintlik om met iemand anders te gesels wat dit verstaan, want hulle... *hulle* gee vir jou perspektief. Jy weet, hulle sê... hulle... hulle laat jou onthou dat jy... mmm... miskien 'n week terug nou nie so erg was nie en jy sal weer daaruit kom... En *al* rede hoekom jy na hulle luister en hulle glo is omdat hulle *self* daardeur gaan... dis *al* rede.

Contact with fellow ME sufferers proved immeasurably important at times of physical distress. Such contact placed her illness in perspective and reminded Natalie that she was not alone, that there were others who understood, and that there would again be a change for the better. In addition, Natalie, as many other ME sufferers do, found it easier to follow someone's advice when that person also suffered from ME. Their shared experiences added a special measure of trust and confidence to the relationship (cf. Franklin & Sullivan 1989: 90). Moreover, it allowed them to care and be cared for as ME sufferers.

Indeed, care, counsel and advice represented important components of the nurturing support received from contact with fellow ME sufferers. Natalie explained:

As 'n mens nou saam met die mense gesels is dit wonderlik dat 'n mens kan kommunikeer en kan uitreik na *mekaar* en vir *mekaar* kan ondersteun, veral *prakties*, jy weet, jy kan vir iemand sê, maar, jy kan... luister, ek weet jy kan nou nie dit doen nie, maar miskien kan jy dit so of so doen... omdat jy dalk al voorheen self daaraan gedink het of so... en... goedjies wat hulle vertel en so aan, dan dink ek, ja, jene, ek het dit ervaar en ek het gedink dis... mmm... baie eienaardig of... of so en dan... sê hulle dit dan... dan half 'n mens... 'n mens put half humor daaruit partykeer, jy weet, jy lag saam of jy... jy huil saam of so... en... dis *baie* goed, dis *baie* positief...

Interaction with other ME sufferers seem to offer an especially rich arena for exchanging information, for listening and learning from the wisdom and experience of others. This is especially important when it is accepted that a little-understood illness such as ME demands an unusual degree of autonomy and responsibility from the sufferer for the maintenance of health. Interaction with those in the know may assist the sufferer to fulfil this responsibility to secure the highest possible level of health and functioning. In addition, ME is a chronic illness. The sufferer cannot strive towards a cure for there is none. Therefore, adjustment rather than cure

offers the sufferer the most favourable outcome (cf. Gallagher & Wrobel 1982: 39-40). The nurturing support of fellow sufferers may here offer a significant contribution in the effort to adjust. Such support may, of course, as Natalie's account suggests, also afford crucial emotional underpinning for all those involved (cf. Collinge 1993: 117; Goldstein 1990: 127).

Thus, on their journey to wellness, participants in this study were met by spontaneous instances of kindness within society. For them, such instances meant being believed and accepted, being helped to render the impossible possible, and being guided to defeat all odds. Aside from such kindness encountered at random, participants also actively sought out nurturing support, and found it in fellow ME sufferers. Among those whose journey paralleled their own, participants experienced a profound understanding born from similar experiences as well as a freedom to express, to care, and to be cared for. Through the perspective acquired in witnessing another sufferer's journey the participants in fact received an important degree of reinforcement to persist bravely on their own road to wellness.

Cruel encounters

Participants revealed the essence of the cruelty they encountered in society:

... regtigwaar die oorgrote reaksie van mense is... is negatief... ongelukkig... hulle... het... *altyd* 'n verkeerde reaksie en dit is *altyd* negatief... So, die reaksie is... ag, jene, tog, dit is altyd... baie negatief... (Natalie)

And the demon behind such cruelty? Ignorance:

Daar heers baie onkunde om... omtrent ME as 'n siekte... (Natalie)

It is not an ignorance that stems from the absence of information. It is rather the ignorance which stems from superficial knowledge and misconceptions:

Ek dink net so min mense... ja, di..dis soos 'n bo-lagie van inligting, almal... o, *baie* mense *weet daarvan*, maar *wat* hulle daarvan weet is *heeltemal verkeerd*... So, daai soort onkunde... ek waardeer dit nie baie nie, want dit is *so onwaar*... (Natalie)

The participants say that this ignorance is, at least initially, often hidden behind a pretence of understanding, but soon the disguise falls away. See how Natalie described this process:

Onderwysers, lektore en werknemers probeer baie dikwels aanvanklik voorgee dat hulle geheel ingelig is en dan, wanneer dit kom by die punt wanneer jy iets nie kan lewer nie, dan plaas hulle weer druk. Hulle noem dinge soos dat jy verskonings soek; dat jy lui is... of praktiese probleme... dat jy nie jou tyd reg

beplan nie; dat jy te senuweeagtig is; dat jy te negatief gedink het van die begin af. Aan die ander kant sê baie lektore en onderwysers... vir jou jy dryf jouself te ver; jy is te ambisieus; jy is te perfektionisties; jy brand jouself uit. Dit is al aan my genoem dat ek nie kan hanteer om te verloor nie, daarom is ek siek.

Natalie's words clearly reveal that many members of society do not understand ME and that they simply do not grasp the very nature of this illness. Denise's account lends further substantiation to this impression:

Aanvanklik het ek beleef dat mense nie rêrig verstaan het nie... Mmm... en aanvanklik as jy vir mense gesê het jy het ME dan het hulle nie geweet wat dit is nie en as jy sê jy het 'yuppie griep'... 'o, jy's altyd moeg'... en jy... jy weet jy's altyd moeg, maar dit... dis baie *meer* as dit, *as dit maar al was*... dan... mmm... kon 'n mens dit beter hanteer...

Natalie's experience highlights an important dimension of the ME sufferer's experience of delegitimation: the trivialisation of symptoms. Ware (1999: 313) says that because many of the terms used to describe ME symptoms sound like minor complaints – fatigue, headache, sore throat, muscle pain – this leads to people mistakenly equating profound distress with everyday ailments. Because everyone endures aches and pains from time to time, a sore throat and fatigue, such complaints are often "construed as minor, if discomfiting, consequences of everyday living rather than as indications of serious illness" (Ware 1992: 350). As a result, ME sufferers like Natalie often meet a disconfirming response when they try to explain their illness to an other: "Oh, so you are just tired; well, so am I. So what?"

Society then, often wrongfully equates ME with an experience of tiredness, a symptom we all experience at one time or another. Fatigue, as it is experienced in ME, is not understood either. Denise explained:

... ek haat dit om te sê ek is moeg, want moeg in terme van... *my* moeg en *hulle* moeg is twee verskillende goed... As mense hoor jy is siek is dit algemeen vir hulle om te... sê dat jy oor 'n week weer beter sal wees. As hulle dan moeg is en rus... voel hulle dan beter... dis asof hulle die konsep rus nog nie rêrig verstaan nie... vir hulle is rus... jy's moeg en jy gaan lê 'n uur op jou bed en jy staan op en jy voel beter en jy gaan aan... mmm... hulle besef nie rus is... in terme van ME is totaal iets anders nie...

In society ignorance prevails not only about the concept of ME, but also about the fatigue that accompanies it and with which it is so closely associated. The "meaning, patterns and implications of fatigue in CFS", as Ware (1999: 305) explains, "make it difficult, if not impossible, for persons with this illness to conform to certain culturally prescribed expectations for behaviour". Where long days crammed full with activity are the norm, ME sufferers lag behind. It is simply not a fatigue cured by an hour in bed; it is not cured by any

amount of sleep for that matter. It is utterly and completely different from anything known in "healthy" life. Apparently, such an experience of fatigue falls outside the bounds of comprehension of many members of society.

The participants also indicated that, besides the ignorance about ME and the fatigue associated with it, people do not understand the chronic nature of the illness. Consider Natalie's description:

Met die begin van my siekte was daar ook heelwat mense wat probeer insig kry het, hulle het belangstelling getoon, hulle het my en my ouers kom besoek, maar met die tyd het... en dis nogal 'n belangrike punt: die chroniese aard van die siekte, die geweldige langdurigheid daarvan... gesorg dat sosiale ondersteuning maar net opdroog. Mense wil nie altyd iets negatiefs ervaar nie, selfs familie bly weg...

Cheryl related a very similar experience:

... in the beginning, friends, family, acquaintances, the church, everybody rallied round... But as soon... as soon as it became obvious to everybody that I didn't have an... an very, very obvious and recognisable physical illness, I started experiencing people getting a bit tired of this person who was sick all the time... they started becoming more distant... the offers of help would become less frequent... the majority of people were... tired of the fact that I was forever not able to do things...

ME is not an acute or immediate state of illness with a discrete beginning, middle and end. Instead, it represents a complex, unpredictable, ambiguous state. Society is, however, intolerant of ambiguity. Society wants the certainty of knowing what to expect. Society does not know how to deal with chronicity. When it is confronted by it, it responds in less than ideal ways. And for the sufferer this response, as Cheryl's account shows, very often leads to a sense of social isolation. The ambiguous status of ME indeed represents a critical impediment to social interaction. The fact that it is not well-described, explained, recognised or accepted as an illness category makes it hard to explain – "to share with somebody" (Ware 1999: 316).

When society is faced by a seemingly incomprehensible illness, it wants to *see* the signs and the evidence of its existence. With ME, this is not always possible. Natalie reveals why:

... aan die ander kant, is daar die meeste mense wat vir jou sê, ag, maar, jy lyk dan so goed, daar kan rêrig niks met jou verkeerd wees nie... mmm... ek sou sê daar... 'n groot mate van diskriminasie het begin toe... in die sin dat as mense geweet het, het hulle nie geweet... hulle het nie die feite geken nie, so hulle het maar net self geoordeel... So... wat hulle gesien het en wat agter toe deure gebeur het... mmm... jy weet, as jy my hier in die stoel kom neersit het en iemand kom met my gesels, dan sou jy weggaan en sê, nee, maar, jy weet... mmm... alles gaan heel goed daar...

The person suffering from ME may, even while desperately ill, actually appear healthy on the surface. This lack of observable evidence of illness is probably the prime reason for the delegitimation of the disease and for leading others to question the ill person's true state of illness. The ME sufferers do not look sick, they are not pale, thin, in wheelchairs, nor do they sport casts. They may even function normally, at least for a time, in work and social settings. But for society seeing is believing. Our society demands to see a scar, a crutch, a wheelchair or whatever other external sign of illness. If there is no evidence, suspicion sets in. If there is no evidence, there cannot possibly be any illness (cf. Strauss & Glaser 1975: 50). For ME sufferers this lack of understanding – when the severity of the subjective experience of the illness is belied by outward appearance – represents a source of desperate frustration. They simply "look too good to be sick".

Denise's account highlights the dire outcome which follows the "seeing is believing" mentality in society:

... sodra hulle dan agterkom dat jy rêrig siek is... dan verander hulle... heeltemal... Ek weet spesifiek dit het gebeur toe ek begin studeer het... Toe, jy weet, het hulle gesê, 'ME, o ME', jy weet... En... tot op 'n stadium dat ek weer siek geword het... toe het hulle vir my gesê hulle het nie besef ek is rêrig so siek nie, so hulle is jammer dat hulle... dat hulle nie aanvanklik ... verstaan het nie... Ongelukkig is dit half... is dit hartseer dat... dat jy eers half tot die einde van jou... '*you* must come to the end of *your* rope, before *they* realise what's going on'... En elke keer betaal *jy* die prys en moet *jy* weer jou stukke bymekaar kry... maar ten minste voel jy iemand het daaruit iets geleer, al is dit nou net dat mense besef dat as jy siek is, is jy siek... en dat ME nie net... nie net 'n verskoning is nie, maar 'n realiteit.

"You must come to the end of your rope before they realise what's going on"... an incredibly sorrowful and completely unnecessary predicament. Why should the ME sufferer be forced to bear aggravated suffering before society is willing to recognise the existence of ME? Why the impulsive assumption that those who do not carry the required scars are most certainly deliberately deluding society? Because for society, seeing *is* believing. When society cannot see any physical signs and does not understand the signs that are visible, the symptoms either do not exist or are only "imaginary". ME sufferers' complaints and their experiences are therefore often discounted as "not real" (Ware 1992: 352).

When society does not understand an illness and cannot fathom its symptoms it reacts to the sufferer in unfortunate ways, as Natalie's account illustrates:

Ek was... by die Technikon eendag... en ek het *geweldig*... mmm... ek het gevoel of nou gaan flou val, ek het net gevoel hoe my bloeddruk val en so aan... En ek was naby die sekretaresse se kantoor en ek besluit... as ek flou val is dit die beste plek... En ek het ingegaan en... in 'n stoel gaan sit... en iemand

anders het ingekom en vir my gesê... eh... jis, jy lyk vreeslik bleek en ek sê toe vir haar, ja, ek voel vreeslik flou... flouerig. En die sekretaresse het my so gekyk en net gesê, ag, nee-wat, jy sit sommer nou net aan en vir die ander persoon gekyk en gesê, ek is seker daarvan sy sit sommer nou maar net aan. Die woorde '*sit aan*'... ek kon... die *vermeteldheid*, ek kon nie dit glo nie, sy... *wie is sy* om dit te sê of enigsins oor my 'n opinie op te trek of... *in my gesig*... ek het gedink dat... dat die sekretaresse *ongelooflik* onbeskof was en dat daar *geen* verskoning is vir wat sy gesê het nie, *hoegenaamd nie*, al het sy geen kundigheid oor my siekte of enige inligting oor my nie... daar is *geen* verskoning daarvoor nie...

Natalie's outrage is perfectly understandable. When society lacks understanding, it unhesitatingly responds in an ignorant manner - it condemns, blames, denounces and berates. These reactions show the traces of antagonism toward the sick that shine through the social fabric when an illness is not understood and when suspicion instead of sympathy prevails. Such delegitimation denotes what Ware (1999: 312) terms the "systematic disconfirmation of the experience of being ill". For the ME sufferer this response may, as in the case of chronic pain sufferers, represent a very real loss of a "legitimate" world, that is, a world consisting of those ways of being that are culturally valued and defined as normative (Kleinman in Ware 1992: 349).

For the ME sufferers in this study, ignorance did not only mean inappropriate responses. It was also very often accompanied by inane advice. Denise said, for example:

As die woorde 'ruk jou reg' maar net soos 'n towerstaffie kon werk sou dit dinge dalk makliker gemaak het... Wat baie mense nie besef nie is... jy wil, maar jy kan nie, en dat dit soms vir mou meer frustreer om so te wees, as vir hulle om jou so te sien...

Also, consider Cheryl's experience:

... ladies who had never even telephoned me, let alone visited me, telephoned to say what a bad example I was. Others visited but only to tell me to 'pull myself together'... And some even admonished me face to face for being such a bad Christian...

The message is clear: "Pull yourself together – now". Yet, if the ill person is advised to resume control, it implies that whatever is the matter indeed falls under the domain of personal control. In other words, the ME sufferer is held responsible for being ill (cf. Goldstein 1990: 7).

Usually, when a person falls ill, he or she assumes the sick role, the special social position in society occupied by a person who is considered legitimately ill. According to Parson's (in Kotarba 1983: 103) analysis of this position, one of the very distinctive rights granted to a person in this role is that he or she will not be held responsible for his or her condition. The

person who is struck by illness is not only shielded from blame or censure, but is also entitled to sympathy and support, depending on the severity of the condition and the degree of suffering it causes (Gallagher & Wrobel 1982: 37). Why does this not apply to ME? Because society does not understand ME. And where there is no understanding, there is evidently no legitimacy. The ME sufferer is not considered legitimately ill and is, hence, barred from access to the rights that would normally accompany the sick role.

Regarding ME as an "illegitimate illness" has the further result that society refuses to exempt ME sufferers from their normal "healthy life" social obligations. Consider Cheryl's experience in this regard:

At first I received sympathy... and gradually disbelief that I could *still* be ill and then outright requests to take up my role in society again...

But...

... I gradually was *not* able to do my... fulfil my role in... in society... They'd phone up and say, the standard four mums are all going to be doing the cool drinks for the... for the sports day... and I'd have to say, I'm actually not well enough to spend the day out in the sun... or I don't know how I phrased it in those days... because in those days I didn't know what was wrong with me, but I would have to decline... I had to excuse myself from *a lot* of things which, obviously, people didn't understand... made worse by the fact that *I* didn't understand...

Consequently,

I think if the community... had accepted me as ill... and helped *me* to accept I was ill... I *might* have recovered sooner, but I still found myself teaching Sunday School and selling cooldrinks at school sports' day... for example... and attending the usual round of school meetings, church meetings and community-help projects. Obviously I *had* to make excuses at times, but some people went as far as to say that I was not 'pulling my weight' any longer – in other words: plain lazy!

Although Cheryl was challenged every day by routine tasks such as showering and getting dressed, by the utter unpredictability of the illness which made her fail to keep to proper schedules, by her failing communications skills, by the lack of stamina to get things done, and by the constant distraction of chronic pain, she was still expected to fulfil her role within society. She did not enjoy any exemption from former role expectations. This is in sharp contrast with Parson's (in Kotarba 1983: 188) analysis of the sick role. According to this analysis, the occupant of this position has the right to claim exemption from normal obligations and responsibilities. If this does this not hold true in the case of the ME sufferer it can only mean that ME is not recognised enough as a serious and debilitating illness. ME simply does not count as an illness that would justify permission to *not* fulfil normal

obligations and responsibilities... because it is *not* understood, the very nature of ME is *not* understood.

Cheryl's experience hints at a further result of society's lack of understanding: the danger of marginalisation. When the community did not understand Cheryl's illness and thought she was not pulling her weight, it became easy to start shunning her. It is "the incompatibilities between qualities of distress in chronic fatigue syndrome and culturally specific standards for social life" – constant activity, speed, "sheduledness" – that "trigger social processes of marginalisation" (Ware 1999: 305). According to Ware (1999: 305), the "combined effect is to push persons with CFS toward the periphery of their everyday social worlds". That is, while society is speeding along, ME sufferers are left behind.

Unfortunately, the denial of exemption from normal role expectations not only shows a deficit in informal social understanding among the individual members of society. It also demonstrates the absence of more formal validation of the ill person's claim to sickness and to full access to the sick role. Consider Cheryl's experience in this regard:

... I'd had a policy with Old Mutual and they'd refused to pay out, because there's no such illness as ME. And we've been mis... we really then... my kids were still little, it was '94... I could *really* have done with domestic help... And that's what we understood this policy was for, not just for death, but for disablement. And we thought, well, even if we can just pay a housekeeper with the money every month, it would be such a help. So we explained everything to them. I wrote my usual screeds and screeds and screeds. And they just said there was no such illness and they advised us incorrectly. I think we... we were probably into debt for doctor's bills and we took something like three or four thousand... that... as a pay... as a pay... which we shouldn't, but we didn't understand that ME would ever be rec... well, it *isn't* recognised. Leon Yankelowitz remains a lone case at present.

The insurance company refused to formally validate Cheryl's state of illness. Consequently, no exemption from customary responsibilities, even temporarily, could ensue. This experience once again typifies the dire lack of understanding of ME within societal institutions and within society itself.

Clearly, for Cheryl and many other ME sufferers, the prevailing ignorance surrounding ME prevented them from enjoying any sanctioned respite from the obligations of daily life. When an ill person is denied access to the sick role and its accompanying rights, the "normal" rules of society remains applicable. The person is still obligated to fulfil normal role expectations. Failure to live up to these expectations is, as Kotarba (1983: 187-188) as well as Gallagher and Wrobel (1982: 38-39) explain, generally considered "wrong" or "deviant". Thus, when a

person is legitimately ill and his or her illness prevents the fulfilment of normal role expectations, the illness is regarded as deviant. When the person is considered healthy, yet still fails to fulfil normal role expectations, the person – not the illness – is regarded as deviant. Unfortunately, when the participants' experiences are reviewed, it is the latter scenario that in many cases applies to their encounters with society at large.

Thus, the participants in this study experienced many hurtful reactions from society in response to their illness. They identified the culprit behind these reactions as a blatant and pervasive ignorance. Society evidently lacks the smallest degree of understanding of the true nature, presentation and course of ME. In the absence of understanding, it appears to society that the sufferers are not really ill. Consequently, if there is no real illness, there is no reason for them to occupy the sick role. Should sufferers dare attempt to assume the sick role, in conflict with society's ruling, they are condemned as deviant. And why should they not be? As society is quick to point out: ME sufferers are not really – *really* – ill at all.

In response...

Society's often cruel reaction to ME undoubtedly has a profound influence on those who suffer from it. Indeed, Natalie's open admission confirms that participants could not avoid responding to society's judgement of ME:

... dit is *rêrig* nog so dat... dat wat ander mense dink... dit... 'n mens moenie dat dit jou soveel beïnvloed nie, maar dit... dit is deel van hoe jy op die ou end jouself sien. So, ek kom altyd terug na myself toe en dink, goed, *wat* is dit, *hoekom* sal iemand vir my sê jy sit nou net aan, *wat* het hom daai... *wat* het daai saadjie geplant, *wat* was my optrede... jy weet, so dit is vir my baie moeilik...

Natalie's account suggests that the participants attached great importance to society's reaction to ME because it inevitably influenced the way they saw and thought about themselves. In other words, how members of society constructed their illness – and by extension, constructed them – influenced their personal concept of Self, their very identity (cf. Field 1976: 345-347).

For the participants society's construction of ME unfortunately translated into the very real experience of stigma and stigmatisation. Denise disclosed:

... ek het... ek het *baie* die stigma-kant daarvan ervaar... mmm... en dit was nie altyd lekker nie, want jy voel jy is... jy is siek, jy kan nie nou nog die stigma-kant daarvan ook hanteer nie, jy moet net probeer om siel en liggaam aanmekaar te hou...

Indeed, Denise and the other participants experienced that stigmatisation caused society eventually to associate ME with some undesirable quality and difference, perhaps even inferiority. Consider, for instance, Denise's experience in this regard:

... ek dink ongelukkig... *baie* mense het dit gebruik, jy weet, het ME gebruik as 'n verskoning om nie... om nie hulle kant te bring... nie. So, ek dink dit het ook die... die samelewing baie sku gemaak ten opsigte van ME... dat as... as daar iemand is wat... wat gediagnoseerde ME het dat hulle almal half oor dieselfde kam skeer... 'o, jy's een van daai wat nie... nie jou kant wil bring nie'... of... of... of wat ookal...

In Denise's experience, there is a belief among many members of society that those who claim to have ME are simply lazy, indolent dolts who only use ME as an excuse to avoid societal responsibilities. It seems that ME represents to society nothing more than a shoddy justification for lethargy. This encounter with society – and its cruel prejudices – clearly indicates the sinister presence of stigma (cf. Green et al. 1888: 66-72).

Stigma – the social meaning constructed by society to account for ME sufferers' apparent physical impairment – not only aggravated the participants' suffering, but also influenced their personal construction of identity and of Self (Field 1976: 347). In order to create a greater understanding of this process as it operates within the lives of ME sufferers, consider the one area in our society where most of its members find a distinctive identity: work. In our society, the dominant "work ethic" indeed exerts a great pressure on everyone to work, to earn a living, to contribute to society (Franklin & Sullivan 1989: 92). Thus, even though persons with ME lack stamina, they live in a world with strenuous work habits where people are devoting ever more hours to their work. In our society, "jobs define who we are and how we feel about ourselves; success at them is a powerful indicator of the well led life" (Ware 1999: 309).

Yet, those who suffer from ME are frequently not capable of full-time work (Franklin & Sullivan 1989: 92-94). Consider Natalie's description of the severe difficulties faced by a ME sufferer in the workplace:

Dit is weer eens... praktiese probleme wat... wat 'n mens kniehalter en wat indirek 'n mens se selfvertroue aftakel. Werksure is lank en dit is vas... mmm... as ek siek raak is ek bang ek gaan iemand in die steek laat... eh... ek is nog nie so mobiel om ver rond te ry of rond te stap nie, ek vind probleme met trappe... My liggaam raak seer en moeg en siek as ek dalk te veel doen, verkeerde posisies sit, of my hand te veel moet gebruik. Selfs konsentrasie en kreatiwiteit kan 'n probleem lewer wanneer ek siek of moeg is, veral met terugvalle.

Consequently:

... ek het nou onlangs... het iemand een van my werke gesien en hulle wou dit... hulle wou dit gebruik... en natuurlik sal ek dit met ope arms ontvang, ek is baie bly, maar die oomblik toe daai persoon vir my nog werk aanbied en sê, hoor hierso, jy kan nou nog 'n hele reeks goed vir ons doen, toe trek ek kleinkoppie, want ek weet nie in hoe 'n mate ek van nou af tot volgende jaar Februarie gaan krag hê nie, wat van as ek kom in Februarie en ek het net die helfte van die werk gedoen... dis vir my baie moeilik...

Natalie simply could not rely on her body to cope with the expectations entailed in a full-time position. She feared that she would experience pain, that her concentration and creativity would not hold up, that she would let someone down, that she would fail to meet promises. When faced by this array of fears she could not possibly commit herself to any form of full-time work. These concerns, which appear to be shared by sufferers of other severe chronic conditions (cf. Kelly & Dickinson 1997: 259) clearly highlight the sharp contrast between the high activity levels demanded by the modern work situation and the levels that an ME sufferer can muster on a "good day" (Ware 1999: 309).

However, society does not tolerate idleness and certainly not the apparent permanent weakness of illness. Instead, it demands active participation in the occupational environment (cf. Franklin & Sullivan 1989: 92). Natalie responded to these stringent demands and expectations as follows:

... ek *moet* 'n werk hê, dit... dis nou maar net 'n feit, jy weet... en... dis *geweldig frustrerend* vir my... Ek weet nie, dis vir my... die eerste keer in my lewe... dis seker 'n punt waarby ek nou gekom het... ek is nou klaar geswot en ek is nou op hierdie ouderdom en nou besef ek, goed, nou is hierdie... nou is hierdie toekoms daar voor my... dit is... dit is 'n *vreeslike groot probleem*. Dis 'n voltydse ding in jou lewe en daai... daai besluit wat jy gaan neem en daai *werk* wat jy gaan doen is die *belangrikste ding*... jy moet weet jy gaan dit kan doen... So, dis... dis vir my baie moeilik... en dis... dis net moeilik vir my om te verstaan hoekom ek 'n talent gekry het en hoekom ek siek moes word en hoekom ek die twee nou nie kan versoen nie... dis mos *baie... frustrerend*... So... daai deel is *baie* moeilik...

Natalie's words vibrate with sheer frustration and desperation. She wanted to work, but was prevented from doing so by ME. She was scared of not being able to live up to the work ethic of our society. Her inability to meet society's standards plunged her into an experience of failure because somehow she was – in society's eyes – "lacking". But not *only* in *society's* eyes. Society's views became her *own* views, became part of her *own* construction of the Self (cf. Green et al. 1999: 72). Hence, as her inability to prove social competence prevented her from enjoying a full sense of social acceptance and worth, she concurrently experienced a loss of personal value and of self-esteem (cf. Cassell 1991: 53; Strauss & Glaser 1975: 52-53). Now, in her own eyes, she became lacking. She no longer qualified as a "proper person"

(Field 1976: 346). Thus, as Natalie internalised society's views of ME and of work, her own identity changed. It was now "spoiled" (Field 1976: 346).

Natalie's experience of the brutal confrontation between societal expectations and the disabilities caused by ME vividly illustrates the process whereby an illness experience that is so clearly stigmatised by society spoils the ill person's conception of Self. Now, both the illness and the ill person are fixed under the stigmatising glare of society. This shows why, in response to the ways society deals with ME, those who suffer from it may internalise the repeated disconfirming interpretations. Ware (1999: 313) confirms that as a result they may begin to question their own perceptions, eventually asking themselves if they are not perhaps really "only crazy" after all?

Thus, for the participants in this study, society's callous reaction to ME transformed into the stigmatisation of their illness experience. In turn, this reaction exerted a forceful influence on how participants saw and thought about themselves. Through the stigma attached to ME, they became aware of an inability to live up to society's standards, of failing to exhibit sufficient social competence... and they experienced failure, a deficiency, an incompleteness. As their sense of social worth dwindled, so too did their sense of personal value. The stigma that society had attached to ME had now become part of their own construction of Self, of their now spoiled identity. The cruel stigmatisation of an illness had found ultimate expression in the stigmatisation of the ill person as well.

To cope...

Cassell (1991: 53) observed that "while most chronically ill individuals cannot play the game, they rarely stop wanting to". This is also true for the ME sufferers who participated in this study. Although patently aware of the very real difficulties that involvement in society might entail, they remained eager to enter and contribute to society. They wanted to be and feel part of society. They wanted to "play the game".

However, the participants wished that "playing the game" could have been much easier...

Mense se reaksies wissel... daar buite is dit meestal negatief... ai, ek wens dit was anders ... (Natalie)

And:

... ek voel... dit sou *soveel makliker* gewees het as mense 'n ander... uitkyk daaroor gehad het... vir 'n mens self... ...Jy sien, as *ander* mense... as... as die *samelewing*... mmm... *verstaan* het dat dit 'n siekte is, byvoorbeeld, sê maar nou soos hulle kanker sien, *dan* dink ek kan 'n mens baie positief en verrykend opgetree het vir *ander* mense se onthalwe... (Natalie)

If only society did not judge their illness experience so cruelly. If only society did not stigmatise them so wilfully. If only society tried to understand a little more. *If only*...

Had 'if only' contained any hope of realisation, participants' experience could have been much, much different. They could have played the game whole-heartedly, perhaps even despite their illness, perhaps even to the benefit of others. But now 'if only' remains a vain hope. They are left to face an often unsympathetic society.

The participants found it difficult to respond, for how does one respond to a society that so eagerly judges, condemns and stigmatises? Natalie pointedly expressed this dilemma:

... *ek weet net nie hoe om dit te hanteer nie*... joe, *ek weet nie*, ek weet nie hoe om te reageer nie... Ek... ek weet nie, as daar êrens 'n wetboek is met reëls wat vir my kan sê... wat doen 'n mens, want ongelukkig kry ek *seer* en ek is nou al... ek sal *nooit* immuun daarteen raak nie, want ek is net 'n mens. Ek glo dit is... dis partykeer net so onregverdig... ek weet nie hoe hulle kom by... by wat hulle vir my sê nie... En... ek neem hulle nie kwalik nie, maar daar kom darem tye, joe, dat ek dink... *hoe moet ek nou reageer*, want ek kan nie dink aan hoe nie, jy weet, ek kan nie... ek kan nie 'n manier kry nie.

Natalie's account bears witness to the hurt and anguish which sufferers experienced when they desperately looked for a way to cope with society's reaction to ME and those who suffer from it. Because it is so utterly difficult to cope or to know how to cope, neither Natalie nor the other participants always had the answer. For them, their feeble impotence and ineptitude in the face of society's response to their illness represented a severe dilemma, *but* not one that was severe enough to stop them from playing the game. Indeed, despite their incompetence in coping, they wanted to participate, to play the game... there in society, in the world where life is lived.

Consider the following account provided by Natalie as a representative yet remarkable example of the participants' willingness to play the game *and* to face the difficulties that entails:

Dit hang miskien af in watter milieu jy is of... of hoeveel die mense verstaan van jou situasie, hoeveel hulle weet... Miskien sê jy glad nie vir hulle nie... maar dan is daar ander goed wat hulle miskien gaan lees in jou... As jy nou nie, byvoorbeeld, vir iemand sê nie, maar jy moet... byvoorbeeld, ek moet nou...

my... in fotografie, as ons fotografie doen in... in die ateljee is dit redelik fisies... mmm... jy moet opklim en groot swaar balke uithaal en papier daarop rol vir die... vir die backdrops en... nou onlangs het ek... het die... die fotografie-lektor vir my gesê, ja, doen dit, doen dit, doen dit... en ek sê toe vir hom, maar, 'listen, Douglas... I think I'm going to get somebody to help me today, because I... I can't do it today'... En ek het geweet... mmm... ek kon nie op my twee bene staan nie, hoe gaan ek nog klim... Ja, en hy vra toe vir my onmiddelik hoekom, jy weet, nou maar goed, nou... mmm... ek kan of vir hom 'n kort kragtige antwoordjie gee wat niks te doen het met die waarheid nie of ek kan nou maar vir hom sê, jy weet... eh... goed, ek is 'n bietjie siek vandag... En onmiddelik na ek vir hom gesê het, kyk, ek is... ek is siek en ek het net nie vandag so baie krag nie, het hy vir my gesê, ja-nee, hy... hy s... soos hy dit nou opsom is dit 'n sielkundige probleem en hy het die ideale dokter vir my en so... Nou maar, jy weet, nou, okay, nou, my reaksie is, ag, liewe aarde, spaar my net... mmm... dat ek deur hierdie gesprek kom... mmm... volgende keer sal ek stilbly... belowe myself nou.... Dan die volgende keer sal ek miskien stilbly en dan sal dit die oneerlikheid self wees... en dis nie ek nie...

Natalie's account tells of a ME sufferer who tried to play the game in society. She ventured into the public world of society and tried her hand at studying. There she encountered an environment in which she was often expected to perform beyond her physical capabilities. It was an environment unresponsive to and often even dismissive of any account for her physical distress. Within this environment, Natalie simply had to cope. Her endeavour to do just this highlighted two very important questions that demand to be answered when an ill person attempts to cope in society. The first question entails a rather pragmatic consideration, whereas the second revolves around issues of a more moral-ethical kind.

The first question: when faced with very real and inescapable changes and limitations, is the ill person willing to accept and adjust? Natalie found herself in an environment which demanded her to perform strenuous physical tasks that she was not always able to accomplish on her own. If she did not ask for help, she would risk the danger of doing herself harm, if not physically, then at least emotionally. How, then, did she cope with these limitations which stood out so clearly in the glare of the public world?

To cope, Natalie needed to accept the unavoidable limitations imposed by her illness, and the fact that she needed help to perform her tasks. She had to avoid causing damage to her body and so she had to discard the pride and egoism that would prevent her from asking for help. She had to adjust her beliefs so that needing help from others no longer constituted weakness to her. And even if it did, it was not a weakness that would make her any less of a person (Collinge 1993: 98; Franklin & Sullivan 1989: 94-96). By accepting her limitations and adjusting her ideas, she could protect her definition of Self, her identity, from succumbing to

society's crude and stigmatising concept of weakness, illness and ME (cf. Field 1976: 345). This was however not as easy as it may sound.

The second question deals with the dilemma which the sufferer confronts when the opportunity arises to disclose the nature of one's illness: should the sufferer choose honesty or secrecy? Each time that the public world confronted Natalie with the opportunity or the necessity to explain her condition she could be open, or she could dissemble. When she refrained from telling the truth she felt that she was untrue to herself. When she was honest about her situation, she was met by callous ignorance and prejudice.

To cope with this situation Natalie, like every other ME sufferer, has to make a choice. It would be misleading and somewhat naïve to simply assume that such a choice would represent a rational, calculated weighing of the costs and benefits of available options – certainly not in situations permeated by severe emotional and physical strain and agony. It would rather represent a fusion of feeling and thought, of the rational and irrational (cf. Kotarba 1983: 198-199). Combined with this peculiar mixture is the indisputable fact that it is the sufferer who needs to take care of his or her own needs. Natalie needed to protect herself against society's discrediting definition of ME and the ME sufferer (cf. Field 1976: 345). Nobody else would do so. Of course, she could accomplish this through complete avoidance of society's reaction to ME – either by avoiding society itself or by concealing the illness from society. In her study of ME sufferers, Ware (1999: 313) did indeed find that in response to repeated delegitimisation her participants often decided to keep their condition "secret". Yet, this approach runs the risk of disrupting the sufferers' sense of connectedness with others and directs limited energy into efforts to conceal. It may also lead the gap between the experience of illness and the "world of wellness" to widen, leaving sufferers feeling in some strange way as if they don't "really exist". In other words, by avoiding society's response Natalie might quite conceivably have created a denial of her Self and her relation to this world. There is also the danger that by keeping the illness a "secret", ME sufferers deprive themselves of "the catharsis of talking about what is most on their minds and of receiving comfort in discovering there are others who care and may provide help when needed". Ironically, "they also preclude the possibility of being affirmed in their experience of their illness" (Ware 1992: 353). In this way, a secretive approach in dealing with society's response to ME might entail its own type of suffering in the very alienation it may induce. Perhaps a better way to cope would involve a compromise between the Self and others, perhaps even a redefinition of the meaning of honesty for the Self. But perhaps it all ultimately depends, as Natalie indeed suggested, on how much is understood

within the particular context in question (cf. Green et al. 1999: 70-73). In other words, within a context of understanding the need for the protection of Self and identity would be far less pronounced than within a context where ignorance is rampant. Hence, the choice between honesty and secrecy – or how to cope – would depend on the measure of understanding that the sufferer experiences within a particular situation.

Thus, the participants in this study wanted to be involved in society at large; they wanted to "play the game". They longed for a society that would judge less and understand more, but for them this avid desire sadly remained unfulfilled. Still, in spite of a stubbornly opinionated society, they wanted to play the game. But to stay in the game, they needed to find ways and devise tactics designed to cope in and with society. This they did. They recognised the necessity of accepting changes and limitations induced by the illness, but not to let society's judgement of such changes and limitations harm their Self, their identity. They also discovered the power of choice and learned that choice is essential to the understanding of ME within a particular situation. By choosing and making decisions the participants ultimately assumed responsibility for the care and protection of the Self – despite society at large. By making this choice the participants became able to preserve existing social positions and roles or re-fashion them in ways that fostered social integration. In these ways, the disruptive effects of illness – and of society's response to the illness – were minimized.

Conclusion

Participants' experiences in and with society serve to emphasise that "much suffering arises from disturbances between the sick person and the public world" (Cassell 1991: 52-53). Their experiences, indeed, offer a vivid testimony of the disparity between the sick person and society. It is a disparity between their respective wants and needs, perspectives and positions, expectations and objectives. It is a disparity that results in a hostile, almost antagonistic relationship between the sick and society.

On the one hand, the sick, such as the ME sufferers in this study, long for a trusting acceptance, for practical help, for constructive advice and guidance, for crucial emotional support, for sound and reliable information, for a reinforcement of their social and personal worth, and for a freedom from demeaning judgement. They simply want to be *understood*.

Society, on the other hand, responds to an illness through the construction of socially imputed meanings based upon the specific physical impairment. Where a physical impairment is *not* understood, as ME is *not* understood, society responds by delegitimizing and condemning the ill person as deviant, by blaming them for their own condition, and by withholding access to the rights of the sick role. In emphasising the ill person's undesirable difference and inferiority, society distances itself from these "wretched delinquents". In doing so, society's response evokes processes of marginalisation – those "influences that push sick persons towards the periphery of their everyday social worlds" (Ware 1999: 312). As a result of such processes, the ill person is eventually regarded as "slightly less human". This reaction exposes society's intolerance of the not so readily understandable, of the inexplicable, of the ambiguous, of the unpredictable, of the variable, of the non-immediate. It also points to society's unshakeable conviction that what is observable is real – the *only* real reality.

What appears to be at issue here is the struggle over the proper definition of reality in the case of ME – physical or psychosomatic, real or unreal. This struggle will determine whether patients will be accorded the status of sane persons who are genuinely sick and therefore deserving of the right to occupy the sick role. If so, much of their personal (if not physical) suffering will be alleviated. If not, they must continue to deal with the implications of having a "not real" disorder which is only rarely recognised by the medical community, and often blatantly rejected by society.

This is the dire struggle that ME sufferers engage in when they enter society; still they want to be part of it, perhaps because they inevitably are and will always be part of it. Hence, they are compelled to learn to cope in this almost heartless environment. In the process of learning to cope, of overcoming their feeble impotence in the face of society's reaction to their illness, they discover personal responsibility. They become aware of their own power to negate and counter society's corrupt judgement of their illness *and* of them. They assume the power to choose an alternative perspective, to adjust their outlook in order to protect and take care of the Self. They are now ultimately – and perhaps for the first time consciously and competently – responsible for themselves.

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Chapter 16
The person in personhood

What is involved in the subjective experience of illness by ME sufferers? Hitherto, the discoveries made in this study in pursuit of an adequate answer to this question have focused upon sufferers' interaction with their social world, as the first fundamental aspect of the human condition. Now, the focus shifts to the second, equally important, aspect of the human condition: the personhood of the sufferer.

In accordance with the work of Cassell (1991: 37-57), each sufferer is a complex being, a personhood of almost countless, intimately interconnected dimensions. Each dimension is susceptible to injury, damage, hurt and loss. Each dimension carries the potential for suffering that resides within every one of us. Each dimension can be profoundly influenced by a truly life-changing illness such as ME.

Unlike other objects of science, persons such as the ME sufferers involved in this study cannot be reduced into their constitutive parts or dimensions in order to better understand them. Still, without forgoing any respect for the extraordinary complexity of the person, a simple topology of personhood will be presented below. Through this topology, I will seek a greater understanding of ME sufferers' subjective experience of illness, of suffering, as it touches the very essence and integrity of the person in their personhood.

A person... has a relationship with the Self

Strauss and Glaser (1975: 52) contend that in the midst of a serious illness, the ill person's relationship with the Self cannot remain unaltered. Although this does not necessarily entail the development of a hopelessly detached and dubious relationship with the Self, the very efforts made to sustain the Self and its relationship with others will contribute to a changed sense of identity. In the light of the representativity of Natalie's statement, this clearly also holds true for the ME sufferer:

... ek dink die eerste ding wat ek wil sê is dat dit... dit het geweldig baie aan my selfbeeld gedoen... my selfbeeld is 'n *baie-baie groot* aspek van hierdie siekte, want dit het... dit is *heeltemal omver gewerp*, dit het baie verander... in *baie* opsigte het ek 'n goeie selfbeeld... maar dan *êrens* daar is daar vir my so 'n

groot gat wat ek... ervaar en wat... wat vir my *geheel en al* die *idee* gee dat ek het nie 'n selfbeeld het nie, jy sien... en ek dink daai gat het *heeltemal* met my siekte te doen... Laat ek dit so stel... *ek* dink dat as ek gesond was dan sou *daai* deel... *daai* persepsie wat ek het van my selfbeeld... mmm... en dat ek sukkel daarmee en so dat... dit sou tien teen een *nie* daar gewees het nie.

The participants' accounts revealed that the influence of ME on the relationship with the Self became perceptible in a development marked by intensive introspection which evolved into a changed view of the Self. I consider this development as a *process*, though it would be wise to bear in mind that it is not necessarily a development which occurs in a neatly consecutive sequence. There is indeed much room for variation, for alternation, for overlap, for repetition. It is a development that not only transpires over days, months and years, but also occurs within a single instant of existence.

The first phase in the development which brings change into the ME sufferer's relationship with the Self is characteristically marked by denial. Denise concisely described her employment of delusive denial:

Althoewel jy half dood voel en jouself met moeite aan die gang kry, wil jy nie weet jy is siek nie... Ek het gevoel soos 'n 'afkop hoender' wat net moet rondskarrel, met die laaste bietjie lewe in my...

Denise was clearly set to deny any possibility of illness and struggled to maintain normal "healthy" activity – at any price (cf. Friedberg 2000: 59-65).

The practice of denial, intimately combined with the desperate struggle to maintain "normal" activity, is also vividly expressed in Cheryl's account:

Now, in the situation that I am in now... my personality can very easily be perpetuating what's happening to me... But it's... it's not a simple thing to... I mean... strictly speaking who I am is not bad... It's good to want to be organised and on time and... available to people who need you... it... it's all good, that's why it's so difficult to change... you see... because it's not a... it's not actually bad traits, character traits... they're just character traits that are not conducive to getting better, because I won't... I won't allow myself... I won't... I won't actually admit to myself that I'm an invalid... that's... that's probably the... the plainest way of saying it... I've never thought of myself as a sick person... I'm battling to come to terms, after ten years of ME, that I am a sick person... It's crazy... but I don't think... I can't imagine I could change, that's just the way I am... I *want* to feel organised... and I *want* to feel that I'm in... that I'm in control of what my house looks like, what my room looks like, what I look like... Ja, I don't know if I could change... I *want* to make nice meals for my family, I *want* to be available to them when they need to... to talk or they need help...

In the face of an illness that directly challenged her concept of personal significance, competence and value, Cheryl preferred to maintain activity. She did not want to admit to

herself that she was, in fact, seriously ill. She did not want to admit that she could no longer fulfil those roles and obligations which directly contributed to her relationship with her Self. Cheryl did not want to accept that ME was now an inescapable part of her life, and of her relationship with her Self.

The experience of such illusory denial is similarly reflected in Natalie's tenacious questioning of the Self:

Aanvanklik wou ek dit glad nie glo nie... ek was oortuig daarvan dat ek myself om die bos lei... dalk sit ek aan, dalk soek ek 'n verskoning vir iets. Ek het *baie* hard en ondersoekend opgetree teenoor myself... het ek gesweer dat ek besig is om aan te sit, het ek gesweer ek is besig om net, jy weet, ve... geestelike probleme te hê... Dit was... dit was die eienaardigheid self, ek het geheel en al geloof verloor in wie ek is en wie my liggaam is, ek het nie meer geweet wat om te glo nie, want ek kry soveel verskillende seine van myself... jy weet, ek het geheel en al geloof verloor in wie ek was, want ek kon net nie... ek kon verstaan wat... wat aangaan nie... Ek bedoel, ek was... hemel, ek was... mmm... wel, die een dokter het vir my gesê dit lyk asof ek semi-polio het... daar is niks meer in my liggaam wat... wat... jy weet, my spiere wou nie meer saamwerk nie... maar dan sal ek seker net dink, ag, jy weet, dit is nou nie die geval nie... ek... ek dink ek sit nog steeds aan... jy weet, dit was 'n baie... baie... ek het baie skepties teenoor myself geraak, baie... mmm... en dit... meestal dink ek omdat ek nie verstaan het wat aangaan nie...

In consequence, Natalie sadly related:

... ek was baie ongelowig, ek het baie ongelowig *gebly* in myself... ek is baie hard op myself in die sin dat... partykeer wil ek myself nie glo nie, jy weet... Daar kom tye dat ek sê maar nou baie energieloos is en ek byvoorbeeld nie fut het of... of dryfkrag het nie, jy weet, dan sal ek myself nou heeltemal... (sug)... ek sal... myself... ek sal myself bevraagteken, jy weet, *hoekom* het jy nou nie hierdie dryfkrag nie en *hoekom* voel jy nou so... Dit... dit het baie van my selfvertroue van my weggeneem... selfs my aksies... mmm... mens kan sien daar is 'n tekort aan selfvertroue. Die dinge wat ek skep... ek het vertroue daarin verloor... Ek dink by tye, byvoorbeeld, dat ek glad nie kreatief is nie en dit is nie die geval is nie. Dit begin veral baie ernsitig raak wanneer ek... nie kan werk nie... veronderstel ek sukkel met 'n terugval... ek begin myself vertel dat ek werklik lui is, ek gaan selfs sover om my... *teen* my beter wete te dink ek sit aan.

Natalie had developed a strategy to deal with the storm of inexplicable symptoms that had exploded inside her and had now turned into a full-blown onslaught directed towards the Self. Where denial had previously protected her Self from being overwhelmed by her illness, it now prevented her from believing in her own awarenesses, in her Self. Her very being was permeated by self-doubt as the interrogation in search of the "true" agenda behind every perception, every weakness, every strength continued insistently. It is not surprising that this approach has led to a steep decline in Natalie's belief and confidence in her Self.

Thus, denial, as the primary characteristic of the first phase of a changing self-relationship, offers a degree of oblivion, an escape from the acute awareness of illness. Denial would, therefore, appear to provide a simple answer to the problem of suffering for those afflicted by ME. But it has a price. Life becomes a struggle to return to the "normal" person one once was, *before* the illness. It is a constant battle to maintain the significance, the competence and the value of that "normal" person – *whilst being ill*. Denial might become even more expensive when it evolves into self-doubt. Then, it deprives the ill person from unconditional belief and confidence in the Self. The Self becomes the antagonist who cannot be trusted and relied upon. Consequently, the relationship with the Self suffers. The ill person's sense of integrity, of wholeness, is threatened, and personal suffering is exacerbated.

Eventually – or perhaps only occasionally – denial gives way to the second phase in the development of a changing relationship with the Self. This phase comprises an "existential crisis" (Collinge 1993: 188). This crisis involves the often ominous realisation among the ill that they are no longer who they once were, and that they never will be again. Consider Helen's telling account:

At the height of my illness, and for a few years to follow, I felt as though my life had stopped. All that meant a lot to me and that brought me much enjoyment had been taken away... I lost my way of life that was the only way of existence I knew; I lost my sense of security that I found in being goal-orientated and in achieving; I lost a certain amount of self-confidence in that the person I had portrayed myself to be was crumbling before my own eyes...

For Helen, such profound change of the Self was accompanied by an intense awareness of loss:

ME represented a time of loss in my life and I found myself actively mourning what I felt I'd lost... I lost my way of life...

With the onset of ME, Helen's usual, "normal" way of life had come to an abrupt halt. Everything her life had stood for, for which she had lived, had somehow stopped. Her life was lost all at once... to an illness.

Natalie related a similar experience of a way of life relinquished to ME:

Op hierdie stadium kon ek basies niks meer doen van my vorige lewe nie; ek kon aan niks meer meedoen nie... En ek het besef daar was nou iets soos 'n 'ou' lewe wat ek moes verruil om 'n 'nuwe' te beplan... 'n Tydperk van hartseer het vir my aangebreek, ek moes dit verwerk... Ek het seer gevoel oor wat ek verloor het en wat ek klaar mis en ek het gesien... wat om my aangaan, hoe ander mense groei, en ek het gevoel dat daar 'n klip in my pad gerol is.

Natalie suffered as she lost her Self in relation to the world of objects, events and relationships which had constituted her "old life". Such suffering occurs "because our intactness as persons, our coherence and integrity, come not only from intactness of the body but from the wholeness of the web of relationships with Self and others" (Cassell 1991: 40). Natalie's "wholeness" had been disrupted. Hence, she experienced a hurt-filled sensation of loss.

Naturally, sufferers' realisation of "a life lost", of "an existence relinquished", releases a turmoil of emotions. Denise expressed an experience of frustration and rebellion:

Jy vra vrae van 'hoekom ek?' en 'hoekom nou?'... en is desperaat... Jy wonder met tye hoekom jy 'n 'oumens lewe' moet leef as jy nog so jonk is. Dit was swaar om op jou bed te lê en droom... en te dink dat jy nou weer kans sien vir die lewe... net om as jy op jou voete is en langs jou bed staan... te besef jy het net genoeg krag om weer te gaan lê...

A deep sense of frustration and disappointment runs through Denise's account. There are so many questions that linger without answers, so many hopes and dreams that repeatedly die in disappointment.

A similar sense of frustration and desperation shines through Cheryl's words:

Basically I see myself as less useful... that about sums it up! And on bad days as completely useless! I *loved* to help my family and friends... it gave me great pleasure. Now I feel boring... always talking about ME or so it seems to me, self-centred and needy. I *hate* being needy. Do I really? What a strong word. Well there you are: *I want to have my old life back!*

Natalie expressed a still deeper sense of absolute desperation:

... ek is *so* gefrustreerd en ek... ek *haat* dit om die waarheid te sê en ek sukkel om dit te aanvaar...

She explained...

Dis 'n baie '*vicious*' woord om te gebruik. Ek gebruik daai woord eintlik *nooit* nie. Okay, anders gestel, ek hou nie daarvan nie! Maar dit gaan *dieper* as dit... *Ja*, dit gaan *dieper* as dit. Daar is *baie* emosies daaraan verbonde. Dit gaan... nee, dis sterker as 'hou nie', *definitief*. Ja, ek haat dit. Dit... mmm... dit is nie lekker nie, nee... Emosioneel-gesproke is ek partykeer kwaad daarvoor, ja, *baie kwaad* en... ek hanteer dit nie... ek hanteer dit nie reg partykeer nie, jy sien, en *dan*... dit is *dan* wanneer... wanneer ek dink dis *baie* erg... En ek weet dat daar soveel erger dinge is, maar *dan*... *dan* is ek... *dan*... *dan* is daar oomblikke wat ek dit *haat*, *ja*, dan is ek kwaad en ek voel *so* gefrustreerd. En op daai oomblikke *kan ek nie*... ek weet nie... ek weet nie waar om positiewe dinge te gaan haal nie. En dit is... dit *is so*... ongevraagd om sulke oomblikke te hê, want daar *is* so baie positiewe dinge, maar... dit kom... Ja, dit is... dit is... ek erken dit, dis oop, ek... weet dit ook nou, dis waar, ek haat dit partykeer. *Definitief*!

For Natalie, her intense frustration at being ill with ME at times evolved into sheer hatred. To hate – *truly hate* – is not only a very powerful emotion, but also a frank expression of a very, very deep injury endured by the Self (cf. Cassell 1991: 43-44). Natalie's account of hatred, indeed, offers a striking testimony of the immeasurable suffering which is braved in the face of ME.

For sufferers such as Natalie, absolute desperation sometimes advanced still one step further… to an almost hopeless despondency. Note the sadness in Natalie's words as she recalled such a time of intense suffering:

… dit is… dit is… miskien die naaste in my lewe wat ek net wou opgee en… dit is nie die enigste keer nie, maar… dit was 'n oomblik wat ek ge..gedink as daar 'n… as daar 'n manier is wat ek myself kan doodkry dan sal ek… sal ek dalk dit kan probeer… ek het nog nooit die moed gehad vir so iets nie… maar, ek bedoel… al is jy heeltemal realisties en rasioneel, is dit nog steeds so 'n emosionele ding… dis… dis baie moeilik…

To suffer from a bewildering illness which challenges every fibre of one's being on every possible level of existence is indeed extremely difficult to bear, and occasionally completely unbearable.

Thus, the second phase of the Self's changing relationship with itself is marked by an existential crisis, a crisis of being. What has been, no longer is. I no longer am who I was. The Self has endured deeply felt loss and injury. It is embroiled in a state of disruption. And it is suffering.

How does the Self respond to its inner disruption and discord? How does it restore its integrity? Where does the Self's relationship with itself lead next? The third and last phase begins to answer these questions. This phase explicitly involves "a turning inward" (Collinge 1993: 192) as the ill person develops a greater receptivity toward what is being heard and felt by the Self. Helen provided a striking account of such a new-found openness to the Self:

ME was my body's way of telling me I couldn't go on living the way I was and stressing my body to the extreme… ME made me stop and refocus… made me question what was important to me and made me realise that very little could be more important than a healthy body… I came to realise the importance of balance in my life… to create a balance between those activities that drained me of intellectual and emotional energy and those that replenished this energy through relaxation and pleasurable activities. I realised that my worth was not based so largely on my achievements, but on the person I was… Being faced with ill-health… has brought me to be far more appreciative of what I do have and of what I am now able to do…

Indeed:

... what has been remarkable to me, is to know that I had to lose all this in order to regain... to develop a better understanding of the type of person I am, to refocus and acknowledge what is important to me and to accept the need to make changes in my lifestyle...

Losing her health – and in a sense her life – so suddenly and so severely to ME, changed Helen's relationship with her Self. She was forced to stop and reconsider, for suddenly the Self's primary concern was no longer with attaining perfection in every endeavour. The Self's value was no longer determined by what it could accomplish, but simply by the Self it already was. Its focus had shifted. Hence, new values and purposes needed to be defined. A re-evaluation of the Self and the relationship of the Self with itself was in progress. And it revealed that the achievement of balance in life – of utmost integrity – is of paramount importance. For Helen, maintaining such a balance became the primary focus of self-care, the real priority of daily living.

Helen's account typifies an approach that Cassell (1991: 61) describes as "flexibility". Cassell suggests that "suffering is relieved when the threatened or destroyed part of the person is replaced in importance by another aspect". Helen replaced the over-riding goal of reaching perfection in all activities she undertook by an emphasis on balance between accomplishment and replenishment.

Other participants followed similar roads leading to a re-discovery of the Self and a re-kindling of a relationship with the Self. Natalie's account of her journey on this a road is an excellent example:

Ek het... heelwat geleer en gegroei omtrent myself... Ek kan op 'n manier sien wie ek is en myself bekyk in moeilike omstandighede waar ander mense nie kan nie. Ek kan sien hoe ek optree, ek kan sien dat ek heelwat deursettingsvermoë toon, ek kan my prioriteite sien... dat eenvoudige dinge, klein dinge, in die lewe soms baie meer werd is as die grotes... Ek het gesien dat ek altyd sterk wil staan en my siekte goed wil hanteer. Ek doen dit nie altyd nie, maar selfs in moeilike tye bly ek veg en hoop...

She elaborated...

... dit is wonderlik om as 'n ME-lyer te begin fokus op... omdat *groot* goed nie meer vir jou bes..beskore is nie, jy kan nie meer *vreeslike groot* goed doen nie, *klein* goed raak nou spesiaal... dis wonderlik, want 'n ME-lyer kan al hierdie goed begin raaksien, soos verhoudinge met mense en... en so... Dis half asof hulle tot stilstand gedwing word vir 'n tydperk in hulle lewe, waar ander mense net voortgaan en hardloop. Jy sien, die *klein*, wonderlike goed, soos 'n voëltjie in die boom voor jou venster of so, raak nou vir jou vir die eerste keer *baie* meer kosbaar... Ek het 'n baie groot... liefde vir die natuur ontwikkel, want dit is God se skepping, dis vreedsaam en baie terapeuties... Ek het empatie vir mense begin

ontwikkel... Ek oordeel nie so maklik nie, want ek weet dat wat agter ander se toe deure aangaan weet 'n mens nie... Ek het besef hoe min ons as mensdom weet en hoe moeilik dit is om dit te erken... Nou hierdie is... dit is *baie groot* goed, maar baie mense loop *verby* dit, jy weet...

Natalie's re-definition of the Self and the Self's environment is very clearly aimed at the relief of suffering. Each re-definition represents an attempt to minimise the sense of loss and bewilderment evoked by the illness (cf. Field 1976: 348-349). Each re-definition marks an adjustment to accommodate the illness, including the vulnerability and limitations it entails (cf. Friedberg et al. 2000: 59-65). Moreover, each re-definition signifies an important stride towards greater self-acceptance (cf. Collinge 1993: 191-193). Where such a sense of self-acceptance prevails, the sufferer becomes able to pay more attention to the Self, to the inner guidance of the Self, and to re-learn to trust the Self's inner experience of life. Thus, it is a re-definition of the Self which brings the realisation that although the sufferer's life has profoundly and irrevocably changed, it is by no means any less significant.

To re-define the Self and its relationship with itself, as described through Natalie's account, represents a distinctly reiterative process. It ceaselessly continues throughout every moment of every day. As Natalie explained:

Ek het geleer dat 'n mens gaan nooit geheel en al so iets aanvaar nie, nie in my... in my geval nie... en dat ek elke liewe dag van voor af moet begin en aan aanvaarding werk... Dit voel baie dikwels nog vir my, veral as ek siek voel, asof ek maar elke maal opnuut moet baklei om staande te bly... mmm... om tot 'n mate... die regte, volle, positiewe geaardheid te hê... so jy bly die heel tyd daaraan werk...

Natalie acknowledged that there had been a change, a transformation, which required acceptance and accommodation. This acknowledgement found manifestation in a continuous process; a process starting each day anew, forever striving towards the ultimate wholeness of the Self – with itself.

Thus, during the final phase of the development which brings change in the relationship of the Self with itself, the ME sufferer responds to the experience of inner disruption and discord by becoming more open to the Self's experience of life and living. This new-found receptivity prompts a reconsideration – a shift in focus – from "doing" to "being" (cf. Collinge 1993: 97). It is a movement in which a greater acceptance of the Self spills over into a changed perspective of the Self's natural and human environment. It is a movement in which a delicate balance within the Self is restored, inner wholeness reinstated, and suffering relieved.

When faced with an illness that overturns all that has been, how does the sufferer respond? When the Self who was, no longer is, who is the Self-of-now? Is the Self-of-now any good? Does the Self-of-now have any value or significance? Can the Self-of-now be trusted and relied upon? Each of these questions reflects the very real threat posed by a life-changing illness, such as ME is, to the very being of those afflicted by it. The intactness of their personhood is profoundly disrupted. Their Self and their relationship with the Self endure injury, demonstrated by intense, sometimes unbearable emotional turmoil. Their Self truly and utterly suffers. They have to respond, and through their response they re-discover the Self. Hence, instead of withering in the wake of illness, their relationship with the Self grows and evolves unceasingly, from denial to accommodation, from doing to being, from self-doubt to self-acceptance, from discord to balance, from fragmentation to intactness, and ultimately, from suffering to integrity.

A person... has a body

Every person has a body, a basic sense of corporeality or embodiment (Cassell 1991: 42). Kotarba (1983: 203) describes this dimension of personhood as that singular sense of "being-within-the-world" that spearheads all perception, appraisal, exploration and experience of life as it is lived. Cassell (1991: 42) goes on to suggest that every person not only has a body, but also enjoys a distinctive relationship with the body. Every illness intrudes into this relationship.

In a state what Gadow (in Kaufman 1988: 346) calls "primary immediacy", body and Self are united and not distinguished. They exist together as separate from the world. The "lived body" can affect the world and in turn be affected by the world. This relationship exists when we are healthy, when the body is taken for granted and is out of conscious awareness. In contrast, Gadow (in Kaufman 1988: 346) identifies a second state, that of "disrupted immediacy". This state is characterised by incapacity. The Self is constrained by the body, limited by the body's capabilities. Moreover, the body is in conflict with the Self. This relationship characterises serious illness – including ME.

For all the participants in this study, the grand entrance of ME unquestionably entailed a fundamental change in their relationship with the body. Natalie indeed spoke for all when she revealed:

... daar het *definitief* veranderinge ingetree in die wyse waarop ek myself sien... Veranderinge het ingetree ten opsigte van my uiterlike... wat natuurlik 'n mens se siening omtrent jouself beïnvloed...

Participants' accounts showed that a profound change in their relationship with the body resulted from an inner conflict raging between the Self and the body. This self-conflict erupted from a number of sources, each one proclaiming not merely that the body is no longer a friend, but that it has, in fact, turned into the principal enemy of the Self.

The first source of conflict between the Self and the body, as identified in the participants' experiences, concerned the manifestation of the body as a changed, almost unknowable other. Natalie, somewhat despondently, related her encounter with her body as the unknown other:

... ek kan... met geen rede kan ek verklaar, dit is die beste tyd van my lewe, en skielik loop alles verkeerd... dit was 'n totale allegaars wat... wat om my ontwikkel het, jy weet, ek het nie geweet wat... wat gaan aan nie, jy weet...

Considering more specifically the very real changes in her body that had accompanied her illness experience, she added:

As ek dink aan my eie liggaam... mmm... alhoewel ek met die aanvang van my siekte heelwat gewig verloor het, het ek omtrent so 18kg gewig opgetel in die afgelope paar jare en ek sukkel werklik daarmee... Ek het aan die begin van my siekte aan haarverlies gely, dis gelukkig beter... Tot vandag toe ondervind ek ook steeds probleme met my vel... Tydens akute stadiums en terugvalle het ek heelwat ernstige veluitslagte gekry wat m..merke... gelaat het. En dan het 'n mens se velkleur... is... is ook van 'n ander soort... dis hierdie bleek soort velkleur...

In like manner, Cheryl expressed the sense of profound confusion that had clouded the onset of her illness and transformed her body into the unknowable other:

... I just... I didn't know what was happening to me... It was so weird, I had no idea what was going on. I was quite frightened, in fact... it was quite a... it was an enormous shock to become ill over-night like that... I was worried and... I was frightened... mmm.. 'bewildered' was probably the best word at that stage... bewildered...

She also very vividly recalled her experience of a changed body:

... I slipped on... a summer dress, which was normally loose on me, I couldn't fit into it, and I couldn't understand it and... I ... I wore it, but it was very tight and I felt very uncomfortable, I couldn't find anything else that I felt comfortable in... I literally had nothing to wear... I went from my usual size 12... to size 16 and then the size... size 16 became too small... I mean, I went up to about 90 kilograms, eventually, but... in... in big leaps, from 60 to 70, from 70 to 80, and eventually up to about 90-something... I looked... I didn't look my normal self, I was huge, bloated, unattractive, at least I thought I was unattractive... I really struggled to cope with this new body image... being a relatively constant 25

kilograms heavier than I've ever been... even during pregnancies... in my adult life makes me feel most unattractive... And I eat *so* little! I can't believe that I'm so fat! I eat *far* less than I did *before* I got ill... *Far less*... which is my only comfort, a vain woman... that I am, I'm not fat because I'm sitting and eating all the time. It's terrible. *Terrible! Terrible!* My whole body shape has changed.

For Natalie and Cheryl, their illness brought a rupture in their relationship with their body. The physical embodiment of the Self had undergone tremendous change – change which both sufferers found excruciatingly difficult to bear, let alone accept or assimilate as part of the Self. How could this changed being be their own body? For them, the profound nature and extent of the physical changes accompanying ME had effectively rendered the body into an unknown and apparently unknowable entity. It was now a being that somehow stood apart from the Self, indeed, in opposition to the Self (cf. Cassell 1991: 42).

Natalie and Cheryl's accounts tell of truly extensive change and transformation; still, it is but a small part of the entire story of erupting conflict. The very distinctive influence of their illness on their experience of the body caused a second source of conflict between Self and body. Natalie sadly revealed:

Soms sien ek my liggaam... dikwels... as onbetroubaar omdat ek nie kan voorspel hoe my gesondheidstoestand gaan fluktueer van nou tot 'n uur van nou nie... Alhoewel dit irrasioneel is, sien 'n mens jouself later as 'n mens waarop 'n mens net nie kan peiltrek nie. Jy kan nie peiltrek op hom nie, ander mense kan nie peiltrek op hom nie. Jy sukkel om afsprake te maak en dit voel vir jou asof jy 'n onbetroubare persoon geword het. Dit... breek maar stilweg 'n mens se geloof, jou selfvertroue, af en jy voel tog tot 'n mate minderwaardig...

The characteristically unpredictable and variable nature of ME had pervaded Natalie's experience of her body. For Natalie, her body had indeed become an enemy of the Self. She could no longer trust or rely upon her own experience of her body as it simply did not offer any dependable indication of future remission or relapse. In this way, the taken-for-granted quality of the body and its performance was lost. This is an experience shared by those who suffer a stroke. Kaufman (1988: 341) shows that a stroke is an assault on the "natural" sense of Self. Though a stroke is a specific physiological event, the resulting impairments may easily be as diverse and profound as those associated with ME. As a result of these changes, which bring previously accepted boundaries into doubt, the person's body – and in fact his or her total sense of being – is affected. For Natalie, this uncertain state of being rendered her Self vulnerable to feelings of personal unreliability, ineptitude, failing and inferiority (cf. Cassell 1991: 42). Natalie's marred relationship with her body had, therefore, disrupted the wholeness of the Self. It had exacerbated her suffering.

And Natalie *did* sufferer. Consider the following particularly expressive description where she again strongly stressed the utterly disruptive influence of the unpredictable and uncertain nature of her illness:

... ek weet van die... die fluktuering... maar dit is... dit is vir my 'n skok as dit gebeur... dis vir my baie moeilik... hierdie siekte is so onvoorspelbaar, jy kan hom nie vaspen nie, jy kan hom nie beskryf nie... elke dag is anders as die... as die vorige een... En daarom het ek baie vertroue in myself verloor, want ek kan nie... myself half defi... definieer nie, ek kan nie sê, dit is nou soos ek is nie... Ek het nie... ek het nie elke dag 'n af-been nie, sodat ek weet my been is nou af... want die een dag is daai been dalk daar, hy's dalk nie so sterk soos hy kon gewees het nie, maar hy is darem daar, en die volgende dag het ek nie albei my bene nie... So dit is... dit is... dis baie moeilik, want jy weet nie hoe jy more gaan wees nie, jy weet nie oor twee weke hoe jy gaan wees nie...

Natalie's account carries one central message: she never knows. She never knows when her illness will destroy an event, a day, a week. She never knows whether she will awaken debilitated or with enough vigour to conquer the day, let alone how she will feel after an hour or two. She never knows how to assess the present. She never knows how to plan for the future. She never knows because her illness has an infinite capacity for cruel and disturbing surprises. Dyck (1995: 309-310) shows that a similar sense of unpredictability pervades the experience of women who suffer from multiple sclerosis. In fact, in her study, it was exactly this unpredictability that led most women to withdraw from activities regarded as central to their lives prior to the onset of their illness. Thus, when confronted with the terrible predilection of her illness for untrustworthiness, unreliability, unpredictability and uncertainty, the ill person's relationship with the body suffers dearly (cf. Cassell 1991: 57; Strauss & Glaser 1975: 41).

Participants' relationship with the body was further tormented by another source of self-conflict which flows from the limitations imposed on the Self by a severely ill body. Cheryl was recently crudely reminded of the very real presence of such limitations through the startling onset of a particularly severe relapse:

I went on this lovely trip... and I came home extremely well-rested... So, for about two and a half weeks I was... the best... mmm... the strongest I felt really in years... and... everybody presumed that I was now back to normal, to the extent that I took up all the invitations that came my way... and... mmm... it was wonderful, I had a great time. But then... the crash after that was... *absolutely horrendous*... It was literally two and a half weeks. I remember it, because I had to cancel... at the end of the third week I had to cancel everything that was going to happen... So... of course, I thought it was just temporary... rest up a bit and back to... but it wasn't, it was a whole *year* of relapse... So, I... I *do* have physical limitations... I mean, as much as I'd like to walk... on this beautiful autumn day, I know I wouldn't get past the fence. So, I mean, I'm sensible enough not to go... but... I certainly would have imagined doing it...

There appear to be two imperatives pressing their claims upon Cheryl. The first, the inner imperative, demands of Cheryl to take care of her ill body, to be aware of and respect its needs and limitations. The second imperative, the outer world of activity, desires to maintain what is perceived as a normal existence (cf. Wiener 1975: 72). In the midst of ME, these become two opposing imperatives; self-conflict prevails.

Natalie similarly described the dire impact of ME-inflicted limitations on the Self's avid desire to live as normally as possible:

Dit is baie moeiliklik... vir my om met my liggaam die kursus te voltooi... want elke dag is anders... En die een dag sou ek opgeklim het en die rolletjie bo afgehaal het en die papier opgerol het in die fotografie-laboratorium... en almal sou dit sien, en more sê ek ek kan nie... En dan weet ek voor my siel daar is geen kans dat ek dit kan doen nie, dan probeer ek, en daar maak ek myself ten minste... op een of ander manier seer, as dit nie liggaamlik is nie, tien teen een geestelik of... sielkundig, want... ek dwing myself ver verby wat ek veronderstel is om te doen... Mmm... en dan op miskien die derde dag sê ek net dis... totaal en al ek kan nie, en dan... dan is daardie tipe van... die hele reaksie van die mense om my... dit is... dit is gewoonlik 'n lelike reaksie... Aan die begin het mense mens gehelp, maar as jy dit eers een keer self gedoen het, hoekom dan nie nou weer nie...

Natalie, like all people, did not want to find her Self limited. She did not want to see her Self as unable to achieve what she had set out to accomplish. But she *was* ill; she *was* limited. This awareness of a restricted body significantly threatens the concept of an intact and autonomous Self – as much for ME sufferers as for others who suffer from serious illness (Kaufman 1988: 343). As Natalie experienced a very real disagreement on the one hand between the Self's expectation to accomplish and achieve and, on the one hand, the body's downright inability to deliver the goods, self-conflict prevailed (Cassell 1991: 60).

From the participants' accounts a fourth source of inner conflict between the Self and the body can be identified. This source cruelly dictates that to suffer from ME is to risk personal humiliation and embarrassment. Natalie graphically explained:

Ek baklei nie soseer met die siekte as met elke praktiese probleempie wat... wat elke dag opduik nie... Byvoorbeeld... eh... ek raak kwaad, want hulle het die biblioteek geskuiwe, dis te ver vir my om tot daar te loop... en dan as ek daar kom is ek so moeg en... jy weet, ek is... jy weet, ek het die bewerasies en die sweet tap my af... en dit is nie as gevolg van onfiksheid nie, want ek probeer dit elke dag stap, maar, ek bedoel, ek is so siek, ek is skoon naar... Of... of... jy weet, jy voel nie altyd jy kan... jy kan aan jouself werk nie, fisies nie, soos byvoorbeeld, ek kan nou nie uitgaan gim toe en gaan oefeninge doen om myself reg te maak nie en... ek sal dalk in die klas wees dan sal 'n ou vir my sê, jhas, maar, jy's vet!... (lag)... dan sal ek sê, maar, jis, ek weet, maar wat moet ek nou doen (lag)... So... (lag)... ja... ja, 'n mens vat dit... ek vat dit as humor en hulle weet ek is humoristies, maar... mmm... party dae... kan dit

knaag, dit kan seermaak... en ek dink dan, ag, maar ek kan dan nou niks daaraan doen nie, dan voel ek ongelukkig met wie ek is...

Natalie's account exposes the body's potential for causing humiliation and embarrassment. Finding a walk tiring, feeling faint, being a bit over-weight – simple matters of concern to all of us at some time or another – now dominate her life. The strain and tension caused by these physical problems were exacerbated by her apparent inability to resolve them (cf. Cassell 1991: 57). They were there and she could do nothing about it. This was a miserable awareness, one that rendered her deeply unhappy as it disrupted her relationship with her body and along with it her inner sense of integrity.

The last source of self-conflict is situated in the self's almost boundless frustration with the body. Cheryl very frankly gave expression to this experience:

I feel *so* frustrated with my body... I experience the lack of mobility and energy with *great* frustration. My room is a mess, my correspondence in disarray and often friends 'phone and say 'thank you for your letter or card' and I'll have to say 'what letter?'... I have a suitcase full of 'things to read'... by now more than two years' collection. Will I ever be able to... All this makes the continued descent into less and less 'brain power' *very* distressing. I felt, and still feel, very clearly that my brain and my body were letting me down... the loss of cognitive abilities was very sad to me... And now... now to be seen as forgetful, unable to assimilate knowledge, clumsy in my thought processes and it becoming more and more obvious to outsiders... it *is frustrating... I miss my mind!*

Cheryl's words reflect a sad and almost desperate frustration. Her once splendid body and brain have now succumbed to the destructive influence of an illness. Through this submission to illness – the very real loss of the body-that-was – it let the Self down. It has betrayed a pact of guaranteed unity and wholeness between the Self and the body. For the Self, the body has turned into an unreliable, even useless entity.

Natalie shared a similar experience of frustration in the face of a ME-weary body:

... alhoewel ek weet dat 'n mens se uiterlike iets is wat jy moet aanvaar, sou ek graag 'n bietjie meer beheer daaromtrent wou hê... Ek wil graag 'n bietjie gewig verloor en so aan, maar dit is net so *moeilik* as 'n mens nog soveel ander goed het... Ag... dis... dis... ek dink dit is *keuses* wat ander mense kan maak, wat jy mee sukkel. Ek *kan nie* gaan oefening doen nie, ek mis dit *verskriklik*... Ek weet die grootste probleem wat ek het is... eh... ek glo dat as ek fisies gesond kan wees dan sou ek al die krag kan hê om verder te werk aan myself, maar nou om elke liewe aardelike dag op te staan en... moeg te wees en seer te wees... en dit gaan rêrig nie meer weg nie... en dit is... dis net vir my... dis verskriklik frustrerend...

Natalie's deep-felt frustration sprung from her perceived inability to exert any control over her body. She would dearly like to change her body. She would like to change its appearance and performance. She would like to change its experience of fatigue and pain. Yet, Natalie encountered an absence of choice and control. As her ability to exert control declined, so her level of frustration increased, as did her experience of suffering.

When the body is invaded by illness, the Self's relationship with the body is profoundly disrupted. The ill person is indeed caught in a fierce conflict between the Self and the body. The body has undergone such tremendous change that the Self no longer feels as though it knows this strange entity. Indeed, instead of knowing it as intimately as only a Self can, it experiences the body as an adversary, an enemy. The body has, after all, proven itself to be unreliable, untrustworthy and unpredictable. It has inflicted exorbitant restrictions and limitations on the Self. It has exposed the Self to the ominous risk of embarrassment and humiliation. And now, to top it all off, the Self is plunged into unending frustration. Moreover, the rupture between Self and body is exacerbated by the Self's apparent inability to exert control, to resolve the conflict, to restore the wholeness. Where such rupture continues unchecked, inner integrity is threatened and magnified suffering looms.

According to Cassell (1991: 57-58), the disruption of self-conflict introduces the very real possibility of discord between body and Self. Discord, in turn, threatens the wholeness of the person, and invites more suffering. Hence, the ill person is forced to respond. Although the ill person, embroiled in the struggle between Self and body, may not consciously perceive different possibilities, Cassell (1991: 58) stresses that "there are always alternatives". The ill person appears to have (or at least to potentially have) access to three options when discord between Self and body threateningly draws near.

Firstly, the ill person, overwhelmed by the suffering of relentless self-conflict, may simply give up and choose to die (Cassell 1991: 58). But, as Cassell is quick to acknowledge, dying is not so easy – "one wants to live, not die". To give up seems cowardly. On the other hand, to *not* give up appears to invite further inevitable suffering.

When the ill person is unable to remove the Self from the situation, a second alternative is called for. Cassell (1991: 60) suggests that the ill person can choose to develop "total indifference" to the suffering. In other words, the ill person assumes "a stance of absolute unconcern to the fate of the body... one allows the physical distress to roll over oneself as a

wave on the beach rolls over a pebble". Cassell argues that this strategy relieves suffering for two reasons. Firstly, to be indifferent to the existence of the body is to remove the very basis for suffering, that is, the loss of the person's integrity. If there is no body, there is no reason for conflict. If there is no conflict, there is no threat to wholeness. If there is no threat to wholeness, there is no suffering. Secondly, as resistance to suffering always heightens the distress experienced, suffering would be diminished once the ill person's resistance is countermanded through total indifference. Still, very few people are able to stop fighting. Indeed, the more they suffer, the more they struggle.

As most people apparently choose neither to die nor to stop struggling, there must certainly be a third alternative. Strauss and Glaser (1975: 34) contend that the ill person, especially the chronically ill person, develops an intense awareness of the body. This means that the ill person learns, in detail, about the nature, patterns, and consequences of the signs and symptoms that accompany the particular illness. When do symptoms appear? How long do they last? Can they be prevented? Can their duration be shortened? Can their intensity be minimised? What is the nature of their influence? In short, the ill person tunes into the body and learns to recognise what the body is saying at any particular moment.

The development of a discerning awareness of the body represents the dominant strategy employed by the participants in this study as they responded to the threatening discord between Self and body. Consider, for instance, Helen's representative response:

To cope with ME physically... I was compelled to listen to my body and to become aware of its warning signs when I was close to a relapse... I have made it my responsibility to look after my body...

Helen resolved to care for her body by listening more vigilantly and keenly to the sensations and impressions it emitted. However, all participants realised that to listen but not to react is simply not sufficient. Instead, achieving genuine alleviation of the conflict between Self and body boldly demands that all listening be accompanied by action. In choosing a particular course of action, the ill person is again faced with a number of alternatives.

Firstly, the ill person may *listen and act excessively*. Wessely et al. (1998: 277) contend that a heightened awareness of the body may lead to excessive "body watching". Through such "body watching" a vicious circle comes into play. As the ill person becomes increasingly aware of bodily distress, the experience of illness is intensified, perhaps even distorted. In response to what is being heard, the ill person opts to restrict activity in order to cope with the perceived (perhaps exaggerated) bodily distress. Yet, the more activity is avoided, the worse

the symptoms become when activity is attempted once again. This provides further validation of the accuracy of the person's beliefs about his or her illness and leads to further concern about the body and bodily distress. Thus, an excessive awareness of the body reinforce illness beliefs and illness behaviour, leaving the ill person destitute in a vicious circle of an ever increasing concern about the body, an ever increasing perception of bodily distress, and an ever increasing restriction of activity. Certainly, this leads to an ever increasing experience of suffering.

Fortunately the participants' experiences revealed that the ill person may choose a different course of action. This is to *listen and act insufficiently*. Cheryl's experience illustrates this particular course of action very clearly:

... there's... times... when I'm just on the verge of coming out of an awful time... where I'll push myself to fulfil what I believe was an obligation... and... mmm... will pay the penalty for it... and that's typical... I... I'll push myself... with dire consequences... For example... my Dad was leaving... and I just had a feeling that it was important to go to the air-port. The 9 o' clock flight left on time and my exuberant sister, her family and my two teenagers... declared the night too young to go home... and... we were off to the Waterfront... I just about burst into tears because I knew I could *not* cope with any more of a night out... I handled it badly and... my husband bore the brunt. That is the sad thing... On the way home I was cross with him for putting me in that awkward position of feeling I could not join in with the fun and just really sat looking miserable until I was taken home... My husband, quite understandably, said if I'd been so near to exhaustion I should have admitted I could not even go to the airport in the first place. He was quite right of course, but I do this over and over again.

Cheryl's experience clearly reveals the calamitous consequences of follow when the desires of the heart and mind part company with the abilities of the body. Collinge (1993: 97) observes that when this happens there is a tendency among the ill to argue with the body. Perhaps the limitations of illness are seen as a challenge, perhaps as an obstacle in the way of accommodating significant others, perhaps as a stubborn encumbrance on the road to recapture a former identity... or worse yet, as a sign of bitter defeat. Unfortunately, the more the ill attempt to push through the inescapable limitations of ME, the more likely they are to exacerbate symptoms and trigger even further relapse (cf. Christodoulou et al. 1999: 604-605).

Thus, in an attempt to maintain "normal" activity, the ill person cultivates an "impression of health". The ill person "passes as normal" – even if just for one occasion (Ware 1999: 318). Yet, while the absence of obvious physical signs of illness or visible indicators of disability might make such pretence relatively easy it does, as Cheryl's account suggests, have a price.

The "payback", the exacerbation of symptoms following episodes of overexertion, is a distinguishing feature of ME.

One has to wonder why Cheryl and each of the participants do it when they know what calamitous results will follow when very real physical limitations are blatantly ignored. Why do participants continuously strive to maintain "normal" activity despite being quite aware of the detrimental consequences this might have on their well-being? Why do they listen to their body, but persistently disregard the message?

Cheryl offered an insightful explanation:

One of my biggest faults is *not* admitting my limitations... and it causes *more* trouble than... than it's worth... So... that's my biggest fault... and... and it's my *own* fault. But it's also *very* difficult to overcome, *especially* when you are in... in remission... the moment I feel I've got a bit of energy, you know, I rush back into life with all the joy of wanting to do things that I haven't been able to do for a while... My husband... has now said, 'slow down, Cheryl, you've been really busy lately... why don't you rest...'. Actually this doctor... said to me the same thing, 'when you think you can do a hundred things, please try and do twenty... you know, and space them over three weeks' sort of story... Augh (sigh)... all sorts of sensible advise, *but I don't*. I do everything that I want to do and what I am longing to do and... augh, I just love it, *I just love it*... No, I *can't*... I *cannot* slow down when I'm feeling there is any energy in me... Ja, this is great common sense talking, hey!

Cheryl succeeded in expressing a sentiment echoed throughout the accounts of all participants: they want to live life to its fullest, *without limits*. To do otherwise would be to surrender to the limitations of ME. To surrender represents an almost unbearable prospect, because that would mean that the restrictions posed by the illness are acknowledged and accommodated, the Self is diminished, and suffering is exacerbated. Consequently, whenever ill persons experience the slightest glimmer of energy, they rush back into life – perhaps, just perhaps, the physical consequences will be less severe than the diminution caused to the Self when it subjects itself to enforced restrictions.

In other words, ill persons are at times willing to accept future "payback" as long as they can continue to take part on equal terms with healthy people in the social world. By deciding to participate *and pay the price*, these individuals can function for short periods as if they were not ill. For them it is a simple choice between having a life and having to pay the price for it, or having no life at all. They choose the former. They immerse themselves completely in family outings, recreational activities, house projects, business trips – matching the pace set by

others and missing nothing. Then they "pay" with increased pain, fatigue and debilitation, knowing that for them it is "worth the price" (Ware 1999: 318-319).

Clearly it is not advisable to respond insufficiently to what the body says. Although it might protect the Self from utter diminution, it nevertheless causes great damage to the body. Hence, from the participant's experiences a third course of action emerges, namely to *listen and act appropriately*. Denise explained:

Dit is nog met tye moeilik, jy... jy wil graag meer hooi op jou vurk laai as wat jy kan behartig... maar ek dink jy leer om rustiger te wees... ja, jy... ek dink tog ek het rustiger geword... veral omdat... omdat ek *gedwing* was om te leer om rustiger te word... Ek dink... ek dink tog ek leer om... om *balans* te kry en te luister na wat my liggaam sê...

Although it remained difficult to resist participation in too many activities, Denise had learned that there was a definite need for balance. This conviction compares very closely to the normalising strategy described by Wiener (1975: 80) as the "the precarious balancing of options". He explains that various and often diverse options are constantly presenting themselves to the ill person: whether to keep up and suffer the increased pain and fatigue; whether to cover up and risk inability to justify inaction when required to do so, whether to elicit help and risk loss of normalising. By making a balancing decision, the ill person establishes an uneasy equilibrium between excessive abnormalisation and insistent super-normalisation. In terms of ME it is an equilibrium in a constant state of revision because this illness is notoriously uncertain and unpredictable. ME sufferers are, therefore, unable to rest easily or for any length of time on previous decisions. In addition, they are inevitably faced by options which have already been limited by their reduced mobility, strength and energy. Still, even amid such variability and restriction, sufferers *do* have options; they *do* have choices. Their decision to engage in one activity but not in another is firmly under conscious control. Whether or not their decisions are appropriate responses to what their body is telling them are their own responsibility. In short, the balance is in their hands.

Thus, in the face of a seemingly uncontrollable rupture between body and Self, participants had to respond. They opted to soften the conflict through granting closer attention to the inner voice of the body and as they listened, they reacted. Their reactions revealed that the desired course of action involved neither abnormalisation through excessive restriction, nor persistent super-normalisation at the expense of the body. The desired course of action, instead, led towards an ultimate balance in which both activity and restriction could be incorporated *if*, and only *if*, personal responsibility for the body was accepted.

The ME sufferer's relationship with the body has been vastly transformed through the changes brought about in the body by illness. The body has become a stranger to the Self, a foreign being that refuses to act and behave as expected and desired by the Self. It fails the Self – repeatedly, surprisingly, and in obscure ways. Consequently, conflict erupts because the Self's expectations and the body's abilities no longer converge. There is disharmony and inner integrity is threatened. Suffering looms despairingly. The Self must respond to avoid irrevocable dissent with the body. And through its response, the Self's relationship with the body changes still further. The Self resolutely tries to become better acquainted with this foreign being, the body. As it learns more and more, the Self reacts to what has been learned. Sometimes, the Self under-estimates the body; often, it over-estimates it. At other times the Self finds a balance that suits both the Self and the body. It is a precarious balance involving a deliberate, yet always uncertain, compromise between activity and restriction. Through this balance a new dimension is introduced into the Self-body relationship: the Self is now responsible for the body – not simply to listen and act haphazardly – but to make a choice that reflects the interests, expectations and abilities of Self and body *combined*. Through personal responsibility, the Self has now become empowered to lower the tension in the conflict with the body. It has warded off the threat to inner wholeness and integrity. It has alleviated the suffering of a disrupted personhood.

A person... does things

Persons do things: "they act, create, make, take apart, put together, wind, unwind, cause to be, cause to vanish" (Cassell 1991: 41). What persons do, what they choose to do, what they value to do, signify and describe who they are. Cassell (1991: 166), indeed, eloquently asserts that actions "write the narrative of our lives". It is an intricate narrative, "an aesthetic whole – a tapestry woven from individual threads to form a coherent pattern that is complete in itself but that also tells of the weaver" (Cassell 1991: 166-167). Thus, it is through the innumerable actions, the small and the large, the mundane and the momentous, of a person's life that a person knows the Self and is known by others. Consequently, when illness intrudes and makes it impossible for persons to perform those actions, they identify with the very fact of their being; they are not whole, they are not themselves. In short, when illness impedes action, the Self is compromised, and suffering ensues.

The participants in this study were implacably confronted by their own illness-induced *in*action, *in*ability, *in*capacity. Consider Denise's concise disclosure:

En toe op 'n stadium het ek rêrig begin depressief word, want ek kon nie doen wat ek wou doen nie... jy is net plein depressief, want jy kry nie gedoen wat jy wil doen nie... en jy kry nie gedoen wat jy moet doen nie en... jy kan nie doen wat vir jou lekker is om te doen nie... jy weet, as ek gaan fliek dan raak jy aan die slaap en as ek pizza's eet dan word ek naar, so wat... jy weet...

When ME interrupted her life, every action through which Denise had known her Self suddenly became impossible to perform. As a person knows the Self to be well by the way it behaves, each in-action, each non-performance, pierced Denise's being with the disheartening realisation that she was now ill, that she could no longer *do*. This experience is strongly echoed in Monks' (1995: 460) study on the illness experience associated with multiple sclerosis.

When participants could not do, could not act, could not perform, and could not accomplish, severe frustration followed. In her particularly illustrative account, Cheryl gave a voice to ME sufferers' experience of such frustration:

... the very real problem of my day/night sleep reversal pattern means... I can no longer schedule morning appointments... and on a Saturday when my husband can drive me somewhere, the afternoons are useless for doctors, dentists, post offices, my hairdresser, banks and things like appointments with insurance companies and most businesses... I can so seldom manage outings anyway, that I then try and fit in too much and... wheelchair and all... there's not much I can accomplish in the two hours I still have of shopping time... Very frustrating... Also... I would prefer to shop in quieter areas, but none of these shops stay open in the afternoons on Saturdays. Then to top it all, I am wide-awake just as the entire family is getting ready for *bed*! So I face a very long, lonely night... sometimes only getting to sleep at 6 AM, but generally... hopefully... between 3:30 AM and 4:30 AM. This is currently one of ME's worst influences on my life, aside from the pain and bodily symptoms. I have tried literally everything to force my sleep pattern back to normal, but even sleeping tablets have no effect in getting me off to sleep around 10 PM when my busy family collapses.

A distorted sleep pattern is only one symptom of ME, yet for Cheryl it carried a magnitude of repercussions. Frustration followed upon each repercussion, for regardless of any and all attempts to rectify the situation, Cheryl was simply unable to do, to behave, to act, as the Self desired. Each repercussion disfigured her tapestry of Self – and increased her suffering.

Cheryl's graphic experience of *not* being able to *do* clearly supports Collinge (1993: 194) contention that "much of the suffering brought by CFS is... a result of having to cope with the

limitations on our ability to *do* things". When Cheryl could not *do*, she suffered. So too did Natalie:

Ek sien myself ook nie prakties genoeg volwasse vir my ouderdom nie. Dit was voor my siekte glad nie die geval nie... Algemene take wat nou vir my moeilik is, byvoorbeeld, huishoudelike take waartoe jy nie 'n bydrae kan lewer nie laat 'n mens nutteloos voel. Jou vordering ten opsigte van dinge in die lewe, byvoorbeeld, om 'n huishouding te kan behartig of om te kan bestuur... mmm... die feit dat jy nié kan nie gee jou 'n gevoel dat jy nie so vernuftig is nie en jy word so afhanklik van ander mense... Dis 'n persoon wat 'n mens nie graag wil wees nie... Ek sien myself as iemand wat bloot net 'n las kan wees vir ander.

Natalie's account reveals that from experiencing the Self as *limited in action* it was but a short step to experiencing the Self as *limited* – period. The Self, the one seemingly unable to perform even the most trivial and mundane tasks, was now – as a whole – insufficient, deficient, incompetent. And, perhaps worst of all, the Self was now utterly dependent on others. For Natalie and the other participants, as for the women in Dyck's (1995: 314) study on multiple sclerosis and Kaufman's (1988: 344-345) study on stroke sufferers, dependency on especially family and friends for accomplishing simple household tasks or for mobility outside the house was something they strongly resisted. Natalie clearly felt that such a dependent Self could not be anything but an onerous encumbrance to others. Unfortunately, when Natalie's Self turned into a loathsome, incapacitated entity, it evolved simultaneously into a source of great distress and suffering (Cassell 1991: 42).

For participants such suffering was gravely exacerbated by the almost inevitable experience of loss in the face of the inability to do things which the illness inflicted upon them. Natalie's recollection vividly expresses this:

Ek moes geheel en al my buitemuurse aktiwiteite staak. Dit het ingesluit dansopleiding, dramaklasse, fisiese oefening... mmm... ek het geswem en gedraf... enige iets wat 'n gesonde, sterk liggaam... wat beweging benodig en so 'n liggaam benodig moes ek opgee... Ek kon glad nie meer, byvoorbeeld, kitaarspel beoefen nie – dit was te pynlik vir my vingers, my vingers was te swak. My stembande was aangetas – dit was pynlik om te sing, om selfs te praat. Boonop het ek nie eens meer na musiek geluister nie, want my ore was te sensitief... Nie eens 'n eenvoudige belangstelling soos die skryf van lirieke of gedigte is iets wat ek meer kon beoefen nie... Vandag kan ek steeds nie die meeste van hierdie aktiwiteite beoefen nie en ek moes die meeste van die dinge wat my belangstellings was en wat voorheen tog tot 'n mate gevorm het wie ek is, moet ek agterweë laat...

Natalie's words reveal a sense of tragic sadness and loss. When ME entered her life it demanded an incredibly high price: it demanded of Natalie to give up and relinquish every action that had up until then given purpose and meaning to her life. It propelled her into

"experiences of surrender" (Schmidt 1999: 22); it corroded her tapestry of Self and it aggravated her suffering.

Cheryl revealed a similar experience of loss and surrender in the face of ME:

I gradually gave up everything... library duty... all sport obviously and I cancelled my second year of Bible Study at College. Any thoughts of continuing an English and Latin B.A. did not even cross my mind... I miss greatly being able to study, write articles for magazines, read my favourite non-fiction...

And still *more* loss, *more* forfeiture, *more* surrender:

I continued to have to give up more and more... For example, I was well known for entertaining and good cooking... I have one friend now who invites us over for delicious meals once in a while, but I met her post-ME and have *never* been able to cook a meal for her family! One very 'good' day she stopped by to find me baking... a very rare occurrence... half the ingredients had *expired*!... and was quite overwhelmed by some very simple coconut biscuits. Now these biscuits, for example, pre-ME would be simply standard fare... certainly not an achievement of note in the kitchen! I used to bake superb creations... I miss this *very* much...

Those activities that had filled Cheryl's life with direction and significance – involvement in the community, physical activity, knowledge and learning, entertainment of family and friends – was lost to the invasion of illness. Such enforced relinquishing of activities did not merely represent a loss of an assemblage of empirical doings. Rather, ME had vandalised the delicate tapestry woven by Cheryl's everyday activities. With her tapestry marred, she was no longer the Self she once was.

When illness pierces the being of a sufferer it inevitably follows that many activities and the ability to continue doing as usual has to be surrendered. For the sufferer, *not* being able to do constitutes a frustration-filled loss of meaning giving activity. It constitutes the bit-by-bit unravelling of the numerous threads of activity in the tapestry of Self. It constitutes a corrosion of inner integrity, because the Self-who-does had now irrevocably changed. As all participants did, Natalie had to recognise the forcible nature of such change in the Self:

Toe die tydperk wel aanbreek dat ek besef dat ek baie siek is... het ek heelwat ontdekkings oor my situasie begin gemaak... Ek het besef dat wat ek was of dit waarmee ek myself besig gehou het tot... toe en wat myself... mmm... miskien geïdentifiseer het as wie ek was iets van die verlede is. Op hierdie stadium kon ek basies niks meer doen van my vorige lewe nie; ek kon aan niks meer meedoen nie... En ek het besef daar was nou iets soos 'n 'ou' lewe wat ek moes verruil om 'n 'nuwe' te beplan...

Through the experience of non-performance, through the loss of being able to do as before, Natalie's Self and self-worth were compromised. Like the participants in Kaufman's (1988:

344) study on the experience of stroke sufferers, Natalie had lost the ability to perform activities previously central to her life and which was a fundamental means of self-expression. Her sense of Self was disrupted to such an extent that it would never again be who and what it once was. There were now two Selves: the old Self, the has-been, and the new Self, still in the making. Kaufman's (1988: 345) study of stroke sufferers show that they share this experience as the loss of physical abilities reverberate deeply in the image of the Self. As these sufferers tried to resume their prestroke lives, they were faced with profound discrepancies between how they once functioned and how they managed in their new lives. For these sufferers, as for the ME participants in this study, their experiences sharply defined the disparity between the old and the new Self.

The transition from the "old life of doing" to a "new life of doing", as Natalie's account already intimated, clearly calls for adjustment on the part of the Self (cf. Strauss & Glaser 1975: 35-36). Note Denise's candid reflection in this regard:

Mense met ME het 'n spesifieke lewenstyl wat hulle moes *aanleer* om met hulle situasie te cope. Terwyl ek dink mense sonder ME... gaan aan... Mmm... ek dink dis... dis nogal 'n groot verskil... hulle... dinge wat hulle as normaal beskou is nie vir *jou* normaal nie en dinge wat jy as normaal beskou is nie vir *hulle* normaal nie... Mmm... so, ek dink dit is half twee aparte wêrelde...

According to the participants' accounts, the adjustment called for when ME entered their lives was a matter of choice. When challenged to adjust in the face of illness, they could reject or they could respect.

Participants' experiences revealed that when they rejected the call for adjustment, they responded to the change, to the frustration, to the loss, to the threat of inner disruption, by struggling against adjustment, and in favour of continued activity. Within a struggle marked by such a strong emphasis on activity, they felt it disreputable, almost immoral, if they were not able to do.

Natalie's account exposed the manifestation of this struggle in the sufferer's life:

Ek raak baie geïrriteerd met myself, ek... eh... waar ek voorheen sou gaan lê het en tevrede wees met 'nou's dit my rustyd', is dit nou van 'daar is nog so baie goed wat ek moet doen', dat ek amper nie tot ruste kan kom nie en wanneer ek wel rus dan's ek... voel ek... het ek hierdie geweldige skuldgevoelens van... (sug)... ja, jy weet, daar is nog so baie goed om te doen... mmm... is dit 'n goeie besluit om nou te lê? het ek dit rêrig nodig? jy weet, hoe intens is hierdie moegheid nou? Mmm... veral as dit op die beter dae gekom het... dan't ek gewonder was dit... gister was ek nou rêrig eerlik met myself, jy weet, was ek nou rêrig gister so moeg soos wat ek gedink het, kon ek nie maar doen wat ek vandag gedoen het nie...

The Self was not allowed to simply be, because any moment lost in being was a moment less of doing. This clearly reflected a perspective in which external accomplishments constituted the most important dimension of selfhood. The Self was valued by what it could *do*. The Self *was* its actions (cf. Collinge 1993: 194). Hence, the stubborn resistance to any adjustment that would favour *being* at the expense of *doing*.

Despite the struggle to *do,* the fact remains that participants were ill and simply could not always *do*. Still, the struggle *demanded* doing. Hence, sufferers ceaselessly tried to compensate for any non-doing. Natalie again expressed the sufferer's overpowering urge to do:

... 'n mens probeer half op-maak... op 'n manier sê jy vir jouself... jy is nog steeds gelyk aan wat jy was... So, as jy 'n dag mis en jy kry 'n beter dag, dan probeer jy twee maal s... dae se werk doen op daai dag... Ek voel altyd ek probeer aan myself op-maak... Ek het dit nooit besef nie, tot iemand dit eendag vir my gesê het, iemand het vir my gesê, maar, jy probeer nou... jy probeer elke keer op-maak vir wat jy... iemand het vir my gesê, jy doen dit orals, jy doen dit in vriendskappe, jy doen dit orals, as jy nou 'n week uitgemis het dan probeer jy nou, jy weet, harder werk... En... dit werk eintlik nie baie goed so nie... want dan... dan is dit 'n kringloop van... dan put jy jouself maar net weer van voor af uit...

It is a vicious cycle. When doing defines the Self but adjustment to new ways of doing is resisted, the Self is perpetually and relentlessly entangled in attempts to atone for what is not done. Similar to the experience of multiple sclerosis sufferers (Dyck 1995: 310), it is a perpetual struggle to comply with the impossible requirement to do, to act, and to perform as before. It is a struggle that must take its toll on the sufferer's health, and further suffering becomes virtually inevitable.

In this way illness, through preventing the ill person from doing as usual, changed the Self. It created an acute discrepancy between the Self who was able to do and the Self who is now *not* able to do. In response, participants have at times chosen to pursue continued activity – maintain everything as before. However, by refusing adjustment, they addressed neither the lingering discrepancy within the Self nor the intense suffering it provoked.

Fortunately, participants had a different option. The alternative was to "remap" their lives (Dyck 1995: 308) by respecting and complying with the call to adjust. In other words they could decide to redesign and restructure their very way of life or, more pertinently, their every way of doing. Participants' experiences showed that such an endeavour to redesign entailed a combination of distinctive strategies.

The first strategy comprised a definite and deliberate change in perspective. Denise described her new-found perspective on doing:

... jy leer om dankbaar te wees vir klein dinge... jy leer om... dankbaar te wees as jy gaan bad en kan aantrek en uitgaan of werk toe gaan en nie te bad en 'n uur moet wag om... voordat jy krag het om jouself aan te trek en aan te gaan nie... So, dit is sulke dinge waarvoor 'n mens nogal leer om... om dankbaar te wees...

Denise had discovered a novel appreciation of being able to do. To do, regardless of the significance of what was done, became of value – perhaps for the first time. Denise's account also attests to a re-calibration of personal expectations for performance (cf. Ware 1999: 320). Her concept of personal achievement has been altered and she was now ready to settle for doing things "less well" because she had developed an ability to appreciate the *very capacity of doing in itself.*

A change in perspective not only entailed a renewed appreciation of doing, but also an altered view of non-doing. Reflect, for instance, on the following experience related by Natalie:

... ek moes myself ook aanpas by baie dinge... ek is... ek is nog steeds 'n baie sensitiewe kyker... Ek kan goed soos geweld nie verdra nie, ek kan dit nie verdra nie, waar dit voorheen in my lewe vir my niks beteken het nie, ek het gedink dis vreeslik en ek sal dit nie toelaat in my lewe nie, maar nou is dit vir my 'n probleem, dit is iets wat ek nie wil... ek wil... dit ontstel my... baie... maar in... in geringe mates ook, ek bedoel, klein goedjies kan gebeur en ek sal dink dit... dit onstel my nou, miskien waar dit nie moes dalk nie... En... dit sou mis..miskien vir my voorheen 'n morele probleem gewees het, nou is dit vir my meer as moreel, dit is vir my 'n emosionele probleem, ek kan nie... ek is rêrig 'n sensitiewe kyker... om rede dat ek... ek ervaar nou nog dat dit nie vir my voel asof ek goed so maklik en vinnig kan verwerk nie, dit... dit bly nog 'n bietjie... it lingers a bit... jy weet... En daarom, joe... het ek al baie goeters miskien... ja, ek het nie eers tyd daarvoor nie, ek loop sommer net uit...

For Natalie, to *not do* no longer necessarily represented an enforced restriction. To *not do* could also at times constitute a means of self-elected protection of the Self. In fact, through non-doing – choosing not to be coerced – the Self became able to side-step negative or hurtful encounters. Thus, it was an adjustment in the way of doing that encompassed non-doing as a legitimate choice.

A second strategy employed in response to the call for adjustment involved a deliberate effort to prioritise. Speaking for all participants, Denise firmly declared:

So dan het jy geleer om prioriteite nou... vir jou uit te sorteer...

Cheryl provided a telling example of such conscious prioritising:

Gradually... I became quite clever at using a 'once a week' lady who helped in my home, to help me cook and freeze meals and do laundry. We just let the dust accumulate and all other household tasks lie for quite awhile. But clean clothes and a full stomach was my priority... And only once my feet actually stuck to the kitchen floor did I search for paid help to give it a good scrub...

For Cheryl, declining physical capacity resulted in the development of a new approach to domestic work. Cheryl recognised that there was a definite need to prioritise since her limited physical abilities would not allow her to accomplish all she might have preferred to do. Hence, a decision had to be made, one that would discriminate between activities which were merely desirable, and activities which were genuinely necessary. The necessary came first; the desirable only once it had grown into a necessity. In Dyck's (1995: 310) study, women suffering from multiple sclerosis revealed similar approaches to the execution of everyday tasks.

Such intentional prioritising as the direct result of illness was often accompanied by a third and closely related strategy: planning. Denise explained why planning is of such great importance to an ME sufferer:

'n Mens leer om jou aktiwiteite en verpligtinge te beplan. Vir my werk dit soos 'n bankbalans met inkomste en uitgawe... Dit help om 'n maand op te deel in weke en dae... en nie meer as een groot verpligting plus-minus vier maal 'n week te hê nie... Anders daal jou energie balans in die rooi en is jy in die moeilikheid.

Denise's experience interestingly suggests that prioritising is also often accompanied by "trade-offs" (Ware 1999: 320). The ME sufferer sometimes has to sacrifice one activity in order to do another.

Natalie clearly supported the sheer necessity of planning:

'n Mens leer baie belangrik nogal om jou tyd te beplan asook jou aksies. Al is jou siekte nou hoe wisselvallig, 'n mens kan dit nie regtig so vas beplan nie... maar besef jy dat elke... goeie minuut is een wat jy sorgvuldig moet gebruik. Dit is soos druppels water, elkeen is net so ongelooflik kosbaar om 'n dors te kan les, niks maar niks vermors jy nie... As 'n mens nou op een dag êrens moet gaan... moet jy besef dat jy alles op een slag moet doen, sodat jy nie onnodig weer hoef te gaan nie.

For both Denise and Natalie, their illness inevitably imposed restrictions on their ability to do. But instead of completely negating the possibility of doing, such restrictions prompted them to plan more carefully and more deliberately. This tendency to organise and to plan activity was also commented on by several women in Dyck's (1995: 314-316) study on multiple sclerosis.

For her participants as well as for mine, planning re-introduced doing into the realm of the possible and the attainable, despite serious illness.

Lastly, in redesigning their way of doing, participants turned to the creative force of invention. It is, as Cheryl disclosed, invention borne out of utter necessity:

I spend long spells in bed and have found a good way to lift heavy blankets off my legs... especially during severe muscle pain... We use a cheap plastic outside stoop coffee table... a square with all four legs slightly shortened for me. This a recent helpful addition.

Also, note the sparks of invention in Natalie's recollection:

Ook die proses van lê... het probleme opgelewer as gevolg van die feit dat my liggaam pynlik en sensitief was... niks en niemand kon my aanraak nie. Ons moet... moes prakties begin eksperimenteer met wat sal die beste kussings wees, wat is die beste matrasse, wat se kleding kan ek dra, wat se skoene sou gemakliker wees...

These are two brilliant examples of inventiveness on the part of ME sufferers. Cheryl and Natalie experienced a critical need and turned to their own creative resources to meet it. They invented and redesigned, and through their innovation they brought relief, ease and comfort into their world of doing (cf. Strauss & Glaser 1975: 35-36). Dyck's (1995: 313) study of women with multiple sclerosis shows that these women too follow similar patterns of innovation to ease the experience of illness – for themselves and for those around them.

Thus, when confronted with the discrepancy between the Self who was able to do and the Self who now appears incapacitated, the participants often opted to adjust and redesign their ways of doing. They changed their perspective, they prioritised, they planned, and they invented. In and through this process, doing as well as non-doing became of value, possible, and even easier. As these new threads of activity were patterned into the tapestry of their new Selves, inner integrity was once again restored and suffering receded.

The multitude of things a person does are the threads that combine to define the tapestry of the person's Self. When illness prevents the person from doing things, the tapestry unravels. Activities are given up, ways of doing are relinquished, and meaning is lost. Through not being able to do, through each inaction and non-performance, the person grows increasingly aware of a changed and somehow diminished Self. Inner wholeness is lost and suffering ensues. Whether such suffering persists is a matter of choice. The person may persist in maintaining activity, and forever atone for the inability to do. Alternatively, the person may choose to redesign a way of life in which doing, as well as non-doing, are not only embraced

but also consciously converted into the possible. Thus, it is a choice between perpetually reassembling a ragged tapestry or creating a new pattern that will both define and reflect a new Self. The choice belongs purely to the sufferer.

A person... has an awareness of time

According to Cassell (1991: 38-43), a person has an awareness of time. A person has a past, a history that has taken place over time and in places, involving countless others. A person has a present, a here and now of immediate, in-this-moment happenings, each shaped by a past and projected into a future. A person has a perceived future, a life of expectations, hopes and dreams, forever exerting an influence on the person in the now. For each sufferer the personal meaning and experience of illness at once arise from all three levels: from the past, from the here-and-now present, and from the anticipated future.

In Nuttin's (1985: 16) view, "time perspective" consists of a "mental perception" at a certain moment in time "of events that, in reality, happen in temporal succession and with longer or shorter time intervals between them". These "events" – which Nuttin (1985: 17) refers to as "temporal signs" – serve as personal or social "points of reference" to which less important objects are anchored. In each individual life, there are some key events that function as digits on a personal or social clock. They help the individual in the relative temporal localisation of other events. These "reference marks" create "the temporal background against which earlier experiences or projections of future events take shape" (Nuttin 1985: 19). This means that at a given moment, an individual's time perspective is not limited to the object that he or she has in mind, but includes a configuration of temporally localised objects residing within both the past and the future contexts of that moment (Nuttin 1985: 21). This notion closely corresponds to Cottle's (1976: 85) "spatial conceptualisation of time flow" that is marked by an awareness of the relatedness of present, past and future. Through this relatedness the past (through recollection) and the future (through expectation) are contained and reside within the present (Cottle 1976: 86).

When we regard "time perspective" as filled with events, objects and contexts from the present, past and future, it is clear that this perspective is not a pre-existing "empty space". Unlike the very abstract notion of time, time perspective cannot be conceived independently of its content. Indeed, content is "an essential element of time perspective" (Nuttin 1985: 23).

And while open to the influence of the anticipation or memory of someone else's action and its outcomes, the most important contribution to the content of a person's time perspective is made by the objects of personal experiences and tendencies (Nuttin 1985: 27).

Thus, a person has a unique time perspective that consists of a configuration of temporally localised objects that resides in the present, past and future and is distinguished by its highly personal content. In my study the content of the participants' time perspective appeared strikingly moulded by the distinctive nature and impact of their illness. Two features of ME, chronicity and unpredictability, stepped forth as exerting a significant influence on sufferers' awareness of time and, hence, on their illness experience.

Firstly, ME is chronic in nature. It spans over time. It is enduring, lasting, and extending. Natalie's account offered substantial insight into a ME sufferer's experience of chronicity:

'n Groot probleem by my bly maar... die tyd. Die chroniese aard van die siekte en die feit dat ek reeds byna my hele jongmenslewe hieraan spandeer het, laat my soms vir kort rukkies 'n bietjie moedeloos... veral met die tydperk van my studies en nou meer onlangs waar ek begin sien wat ander mense om my vermag... dan sien ek ook wat ek nie regkry nie... Ek... ek kan myself... mmm... beter ondersoek en sien hoe siek ek regtig is en dit laat 'n mens ook moedeloos... Ek het nooit daai groeiproses gehad tot daar nie... mmm... daar is 'n groot deel van my jongmenslewe... dis net... dit is net weg, dit het nooit gebeur nie, ek het nie matriekafskeid toe gegaan nie, ek het nie 'n ou gehad nie... So daai deel is... is nie daar nie... die *groeiproses* waardeur hulle al is wat ek nog nie gedoen het nie, ek... en ek weet nie *wanneer* ek dit gaan doen nie. So, dit is ook iets wat my affekteer... Ek *weet* wat ek gemis het, ek weet... So, dis... dis maar net... dis maar net nou vir my moeilik... dit is... daar is definitief 'n verloop van tyd... ek bedoel... jy sien net soveel dinge wat jy misgeloop het en dan voel jy maar jy het nie al die beheer wat jy wil hê nie...

Natalie elaborated:

... om elke dag moeg te wees en energieloos te wees en vir so 'n *lang* tydperk van jou lewe... gee vir jou 'n hele *ander*... perspektief daaroor en jy voel... goed is moeilik om te hanteer, dis hoe jy deurgaans voel... Dit maak 'n mens *bang* as jy dink dat jy al... *vergeet* het hoe dit voel om gesond te wees... ajh (sug)... Ek het *geen* idee hoe dit voel nie, dis *waar*... Ek het *geen* idee hoe dit voel om *nie* moeg te wees nie, ek is *altyd* moeg. En ek het *geen* idee hoe dit voel om... wel, ek het meeste van die tyd pyn, ten minste êrens, ek het nie altyd *orals* pyn nie, maar ek *het*... En ek het *geen* idee hoe dit voel om... om daai vryheid te hê van... jou liggaam hou jou nie terug nie. So... mmm... dit affekteer my baie... mmm... daar is so 'n tipe van lewensenergie wat net uit jou uitgaan en jy weet nie waar om dit vandaan te kry nie... jy probeer, maar dis weg... Dis... dis moeilik... want dit is al net so lank... Ek hoop... ek hoop dat ek sal nooit moed verloor nie, *heeltemal* nie. 'n M..mens lewe maar saam met daai *vrees* dat daar 'n oomblik gaan kom in jou lewe waar... dit net te veel vir jou gaan word. Ek hoop dit kom *nooit*... maar, ek bedoel, 'n mens dink... 'n mens dink soms daaroor, want as dit so *lank* raak dan... mmm... *sjoe*, dan sien jy dis *moeilik* partykeer om dit te dra, dit word 'n *baie* swaar las...

Natalie's recollection clearly reveals that the chronic nature of her illness and, in particular, the fact that she has devoted almost her entire youth to it, at times leaves her feeling utterly despondent. She cannot but acknowledge the enormity of all that she has *not* experienced, of the personal development, growth and experience of a young adolescent life she never enjoyed. While this is a time lost to her forever, Natalie's account shows that the memory of that time is still vivid and is still able to play a strong (and at this stage unsettling) role in her present. By recapturing her past experiences and relocating them in the present Natalie's account clearly reveals that the past (along with its deeply personal content of chronicity) can indeed reside in the present and there exert a powerful influence on experience in the Here and Now. Thus, for Natalie, memory of the past represents an integral basis for perceiving time and, hence, for experiencing illness in the present (Cottle 1976: 13).

The connection between the experience of time in the presence of a chronic illness was even more pronounced when, speaking after almost ten years of illness, Cheryl candidly revealed:

I'm *really, really, really*... not excited about what I'm learning about the connection between cancer and ME... long-term ME... because your body has suffered for such a long time, your immune system has been battered and... you yourself has been under par for so long... So, there *are* worrying things... worrying things ahead for people who's ME has lingered for so long... So, if I had to be very honest with you now, the thought of being... maybe... mmm... you know, ten or fifteen years away from... from... dying of cancer... is pretty hair-raising... And... I *have* confronted the fact that I might have ME for the rest of my life. And I can't pretend the thought... excites me *at all*. I would... very much... like to think that there was a cure around the corner, but after all I've learned and experienced... I don't think there's a cure. I honestly don't think there's a cure... I've remained... hopeful that I am going to get better... I've only, in the last... mmm... two or three weeks that I've felt so very ill, become... for the first time ever, I can honestly say to you, become... disheartened to the point that I wonder if I'm going to get better, it's happened a few times now... that I've wondered if I'm going to get better... So at the moment I don't see the future... rosily... I'm actually deep down starting to get a little bit frightened that I'm *not* going to get well, for the first time... I haven't... mmm... feared for the future before these last two or three weeks... but I've just been so ill... that I actually... mmm... started thinking sad thoughts...

The chronicity of ME has at times instilled a fear in Cheryl that a body battered by severe illness for such a long time may be exposed to worse affliction. What if she stays ill forever? What if a chronic illness becomes a terminal illness? Indeed, while Cheryl has generally remained hopeful of getting better, times of acute suffering have afflicted her with a grave despondency. At such times the hope of recovery elude her and the fear of permanent illness takes its place. At such times the dread of permanent illness violates the sufferer's perspective on the future. Yet, the future is 'the primary meaning of existentiality'. It gives meaning and purpose; it is filled with intention and possibility. Moreover, as Cassell (1991: 42-3) reminds

us, it is that dimension of existence in which hope dwells. When the future is then lost to anxiety and extreme uncertainty, intense sadness results for "no one has ever questioned the suffering that attends the loss of hope" (Cassell 1991: 43). Thus, when Cheryl defines her future as filled with dread and anxiety, it affects her perspective on the Here and Now as well as her experience of illness and Self.

In accordance with my participants' experiences, the content of their time perspective was not only distinguished by the chronicity of their illness. It was also very strongly affected by the fact that ME is inherently unpredictable. It is variable, unstable, uncertain, even erratic. Besides knowing that over-exertion will trigger "payback", they are unable to guess when a relapse will occur, and at a loss to explain it when it does.

Denise's account clearly reveals the relation between unpredictability and time perspective in the life of a ME sufferer:

Die toekoms is vir my... dis moeilik om nie rêrig te kan planne maak nie... mmm... want dit... dit is nie vir my realisties op hierdie oomblik nie... Jy kan niks beplan nie... nie kort of langtermyn nie want jy weet nie of jy dit sal kan bybring nie... Jou aksies en aktiwiteite word rondom jou energievlakke beplan... wat kan wissel van oomblik tot oomblik... So, jy kan nie jou lewe rêrig organiseer soos wat jy graag sou wou nie... En ook, ek dink 'n mens... mens leer om teleurstelling te hanteer, want daar is dinge waarna jy uitsien en dan ewe skielik is jy siek en jy kan nie daarby uitkom nie... Dit... dit maak jou half skepties in terme van langtermyn-doelwitte... mens sou graag *wil weet* jy... jy werk na iets toe... wat 'n mens op hierdie stadi... wat ek op hierdie stadium *nie* het *nie*, jy weet, op hierdie stadium gaan ek nou maar net aan... Ek dink inherent e..ervaar meeste mense dit, ek dink net met ME is dit... is dit vir jou 'n baie meer *konkrete* komponent... van... gaan jy *fisies* in staat wees om dit te doen? Dit maak dit soms moeilik... jy weet, dis half sleg, 'n mens wil... mens *wil weet*, maar jy weet *nie*...

Historically, only work life was strictly scheduled but, as Ware (1999: 311) points out, "our cultural penchant for 'scheduledness' is expanding into other domains". Now, leisure is scheduled. Social life is scheduled. A full calendar has indeed become "a sign of a successful life". Conversely, a too-empty one is seen as "a source of concern". Yet for the ME sufferer such "scheduledness" is impossible. In fact, while many of us may live our lives by our calendars, "persons with CFS can neither commit to nor follow a schedule, since they can never predict when their fatigue and other symptoms are likely to intensify or recede" (Ware 1999: 305).

For Denise it is simply not a realistic exercise to make any definite plans. After all, her activities are shaped around her physical energy and as the latter fluctuates without warning, so

too does her ability to meet whatever plans have been set. The resultant inability to map out *and* depend on keeping either short- or long-term plans has rendered her sceptical about the potential of constructive planning and goal-setting in her own life. Worse yet, when Denise found herself unable to plan and unable to look forward to her future, she no longer felt in control. After all, as Nuttin (1985: 40) points out, the future is "an essential dimension of a person's behaviorial world and his motivated purposive action". Indeed, "the ability to construct far-distant personal goals and to work toward their realization is an important characteristic" of simply being human (Nuttin 1985: 9). However, when a person's future time perspective is severely limited by the impact of an unpredictable illness, this ability to set goals and make plans and, in effect, to feel in control, becomes jeopardized. This sensation is indeed strongly reflected in Denise's awareness of simply drifting from one moment to the next, without clear direction or purpose, without being able to place herself on the trajectory of her illness, and without being able to anticipate what is to follow (cf. Bury 1997: 114; Dyck 1995: 316; Strauss & Glaser 1975: 47-9).

Similar to Denise's experience, Natalie's account also reveals an austere perspective of time, and specifically of the future, as disrupted by illness:

So, as 'n mens praat oor die toekoms dan is dit 'n langtermyn-ding... en dis waar my probleem lê... Die toekoms is moeilik, want die... die langdurigheid daarvan, die feit dat dit... dat dit nie in 'n moment geskied nie... dis moeilik... Ek dink nie... ek dink nie 'n mens... enige iemand is eintlik... hulle... hulle is nooit rêrig seker nie, so ek... verbly my nou daarin dat ek nie die enigste een is wat so rigtingloos voel nie... Ek het net nooit gedink ek sal so rigtingloos wees nie, ek was nog nooit... my hele lewe lank was dit net... my pad, ek het geweet waar lê my pad... en... ja, nou's dit... mmm... ek sien soms... mmm... ek loop myself vas, ek weet nie waarheen nou nie... omdat my lewe so... moeilik is om *vooruit* te beplan en *vooruit* te kyk...

The sense of future possibility is, as Cottle (1976: 161) explains, first encountered through the very act of planning or intending. So, "in working out these plans, following them, and having them realised, one learns that, to a certain degree, the future can be shaped by one's own efforts". For Natalie, however, the intrusion of illness left hardly any room for definite planning. And where planning was so uncertain, so too was the future. For the future perspective is shaped not only by our specific plans for today and tomorrow, but also by those we conceive for our life as a whole (Barrett in Cottle 1976: 161). In this way, the unpredictability of her illness directly affected Natalie's deepest sense of Self and being. According to Kaufman's (1988: 341) research, this is an experience shared by those who suffer a stroke and face the unpredictable process towards rehabilitation.

The utter unpredictability of ME that has so deeply touched Natalie's sense of Self has also invaded her life of dreams and hopes:

... dan kyk jy in die toekoms en dan sien jy soos byvoorbeeld... goed soos om 'n verhouding te hê met 'n man. Dit is moeilik vir my, want... omdat ek so *wisselvallig* is... mmm... is dit moeilik om van iemand anders te verwag, van *enige iemand* te verwag om saam met jou... mmm... 'n leefstyl... in jou leefstyl in te gaan, want hulle... mmm... dit verskil net baie van gesonde mense... Ek sien nie... wel, ek... ek... ja, ek... ek is baie bang om in 'n verhouding in te gaan en soveel van die persoon te verwag... Ek wil nie iemand se lewe half van hom wegneem nie, ek wil nie uitgaan met 'n ou en as hy vanaand iets wil doen vir hom sê, nee, hoor hierso, ek kan nie... en dit is al die tiende aand in 'n ry wat ek vir hom so sê nie, dit sal baie onregverdig wees teenoor hom... Maar... dit is vir my... mmm... ek is baie... ek dink ek is baie skepties daar... daaroor...

Every person has a secret life, a life of dreams, fantasies, wishes, hopes, and desires with a real existence often known to only a few (Cassell 1991: 42). Atkin and Ahmad (2000: 507) noted how this life can be invaded by worry and apprehension as their participants, sufferers from thalassaemia major, feared that their illness would stand in the way of relationships with potential partners. In much the same way, an important dimension of Natalie's secret life was her dream of an intimate relationship with a special partner. But ME stands in the way, for whenever Natalie dares to think of entering such a relationship, she immediately confronts uncertainty. Natalie's experience indeed corroborates Ware's (1999: 316) finding that the unpredictability of this illness represents "a major impediment to social interaction". Because ME sufferers cannot predict their condition on any given day, they are often forced to cancel set plans at the last minute. And friends take offence at these unexpected changes. After repeated instances they may, as Natalie clearly fears, simply decline further overtures and let the relationship wither away. Indeed, the utter unpredictability of ME has changed Natalie's life so radically that she can no longer conceive of someone who would be willing to accommodate such persistent change and disruption within a relationship. Hence, ME has filled Natalie with the fear of expecting too much and by doing so left her unable to tie the present to the future through hopeful expectations (Cottle 1976: 149). Indeed, the impact of Natalie's illness has impaired her vision, her perspective of the future – the very "building site of constructive behavior and human progress" (Nuttin 1985: 40) – with fear and anxiety.

Natalie continued to disclose that as the unpredictability of ME touched her plans and dreams, it indeed touched and changed her sense of Self:

Iets wat ek wel agtergekom het is dat my gevoelens en siening omtrent myself fluktueer en direk saamgaan met my fisiese. Wanneer ek baie siek voel ervaar ek myself met die minste vertroue en wanneer ek 'n bietjie sterker is mag ek dalk net met meer... aanvaarding aan myself dink. Wanneer ek baie siek en swak is dan is ek negatief... eh... baie meer klaerig, ek voel baie meer minderwaardig, en

as ek sterker is dan is ek meer trots op wat ek vermag ten spyte van die omstandighede... Ek... ek kan miskien *vandag* vir jou sê... mmm... dit is 'n seën in baie opsigte om siek te wees en ek het baie geleer en so aan... en dan die *volgende* dag sê ek vir jou, nee-wat, dit is nie, ek is *so* gefrustreerd en ek... ek *haat* dit om die waarheid te sê en ek sukkel om dit te aanvaar. So, dit wys jou net dat dit... dit hang van dag tot dag af hoe 'n mens voel en ek glo *werklikwaar* dat 'n mens se *fisiese*... bestaan so *groot* invloed het daarop... hoeveel energie jy het, hoeveel pyn jy het... sulke dinge...

For Natalie, the variable and unpredictable nature of her physical well-being resulted in a shifting, unstable sense of Self. As her body waxed and waned under the pressure of ME, so too did her sense of Self. In other words, as "my body is no longer what it was a moment ago", so too to some extent "I am no longer the I who I was". It is in this way that Natalie's shifting position on the trajectory of illness profoundly affected her sense of Self, of personal identity, of stable being (cf. Strauss & Glaser 1975: 52). Unfortunately, where instability and uncertainty marked the Self, inner integrity faltered, and suffering ensued.

Thus, the participants' experience of illness revealed that through perception they were aware of the present. But their time perspective was not limited to the Here and Now. Through memory they recalled and reconstructed their experiential past, while their future came into existence on the level of representation, expectation, and imagination. While this clearly shows that for my participants both their past and their future reside within their present, this was not necessarily ideal. For participants, their past was filled with lived hurts and with the dread of attenuated illness, their future with the anxiety that comes with anticipated distress, severe uncertainty and a sense of diminishing control.

Yet, the participants' experiences also showed that they were not entirely delivered unto the powers of a chronic, unpredictable illness. Cheryl offered us our first insight into an alternative powerful enough to countermand the disruption and anxiety of severe illness:

This is... this is a strange thing... I... I think of it, of a relapse, as an academic possibility... and, in fact, after ten years, if I were to put on the spot, I would know it was a *surety*. I mean, I'm not... I know I'm not... I'm not cured. Symptoms are building up rapidly *as we speak*... today is not a good day... But... but... that is an amazing thing! The optimism is... completely unfounded (laugh)! *Completely unfounded* (laugh)! Not based on fact or past experience... I don't live in fear of a... of a relapse... *at all*... which is *totally*, as I say, it's... it's *totally* abnormal (laugh)... based on past experience (laugh)!

Cheryl's approach suggests that an alternative to the severe experience of anxiety and dread lies right here in the present. In her mind, *in this moment*, a relapse represented only an academic possibility. To be sure, based on past experience, she would probably have to

concede that it is far more likely to happen than not. Still, Cheryl does not dwell on this knowledge. Instead, she maintains the Self wholly in the present moment of Here and Now. Here the relapse is not considered a reality, and it is not feared. Thus, to countermand anxiety, Cheryl deliberately chose no longer to linger in the past of has-been's and could-have-been's. Similarly she saw no use in dreading a future that has not yet come to pass. Instead, Cheryl maintained the Self entirely *in the present moment, the Here and Now*.

According to Cottle (1976: 173), this does not mean that Cheryl is perceiving her present from the point of view of an "observer of action" for this would imply that the present exists for her only on a moment-to-moment basis. This would render "the observer" powerless to change or influence it. Instead of such an instantaneous perception of time, Cheryl's account suggests that she perceives the present as "extended". That is, she is an "agent of action"; she can control the present. In this way, Cheryl discovered and embraced the present as that dimension of existence most likely to be affected by personal choice and control (cf. Cassell 1991: 58-9).

Denise's experiences reveals another dimension: to maintain the Self entirely in the present liberates the sufferer not only from past hurt and impending dread, but also from the rush of interpretations such memories and prospects are likely to evoke:

... dis aanvanklik baie negatief, maar jy... elke negatief het sy positief, so jy... dis 'n negatiewe oms... situasie, maar jou belewenis daarvan, jou hantering daarvan *kan* dit omskep in 'n positiewe situasie... Kyk, jy kan half net die negatiewe kant daarvan raaksien en in 'n hoekie gaan sit en jou aan die slaap huil, maar dit... dit gaan *niks* daaraan verander nie. So, jy vat die positiewe saam met die negatiewe... en ek dink ook 'n mens... mens *leer* om die negatiewe te erken. Jy... mens word half groot met die... met die konsep van dat as iets negatief is dan ignoreer jy dit... terwyl *uit* die negatiewe kom daar wel ook die positiewe, so jy het nodig om die negatiewe te erken... mmm... maar jy het *nie* nodig om dit te koester nie.

Denise's account suggests that while certain adverse qualities may be undeniably present within a particular experience, there is no need to treasure such qualities. There is neither any use nor any need to reflect on their counterparts in the past or their potential influence on the next moment. Instead, a different focus can be deliberately adopted, one that may permit a more benign experience and interpretation of the present situation, in the present moment.

This approach reminds us of Schutz's concept of "attention to life". This is the basic regulatory principle of the Self's conscious life, which both defines the realm relevant to the Self and determines the attention directed by the Self to the given experiences. The Self's "attention to life" is, however, no static entity. It is, instead, very much open to modification

and is capable of showing all sorts of shadings: from actual comprehending, to merely noting, to hardly noticing, to leaving completely unobserved (Schutz 1967: 73-4). For the Self, every moment in time – every Here and Now – is constituted by such attentional modifications. Consequently, the interpretation (or meaning) that the Self imputes to experiences depends on those attentional modifications marking the very moment of interpretation, that is, the actual Here and Now from which the Self is looking.

If we follow Denise's approach, it would appear that we should remain consciously aware of the attentional modifications marking the moment of interpretation. In other words, when a sufferer holds her personal time still for a moment of perspective, she becomes aware of these modifications, and so also becomes able to determine the interpretation of actual events. She is, in fact, able to choose an interpretation, a perspective, from which to view the particular instant as well as subsequent events. Cassell (1991: 59) agrees that "the person's choice of interpretation is central to how that person experiences the events – it is the interpretation that determines whether suffering or merely distress is experienced". Events are, in other words, not necessarily inherently positive or negative, good or bad. Instead, the nature of events – as they are experienced – is determined by a personal choice of interpretation.

When the participants held their personal time still, when they lived entirely in the present moment, their distress was relieved, not only because they were able to (re-)interpret the nature of experienced events, but also because they were able to (re-)appraise the Self. Helen's concluding statement to her autobiographical sketch provides persuasive substantiation:

I coped with an illness that has no foreseeable end to it, by trying to stay positive and by trying to concentrate on the invaluable experiences and lessons I could learn from it... It was a time of suffering that I would not wish onto anyone else, but at the same time, was a period in my life I would never wish away either... it brought with it much pain and heartache, but left with me with a much richer and deeper understanding of myself that I will cherish forever.

While Helen's illness clearly represented a time of great suffering, it was also a period in her life that she would not discard because it awarded her with a much deeper understanding of her Self and of the power that resides within her Self. Indeed, for Helen, suffering was mitigated by a distinctly revised appraisal of the Self in the present moment. It was an appraisal of the Self not as powerlessly dictated to by illness, but as powerfully supportive of the Self despite illness (cf. Collinge 1993: 77-8). In the very act of reflecting on the Self, a new context of meaning was created to which experiences are referred for interpretation in the extended present. This process of referral in effect reflects the chosen content of the sufferer's time

perspective through and from which the Self's interpretive glance is operating (cf. Schutz 1967: 78-84).

For participants, it became imperative to refrain from reliving past hurts as well as from continually tumbling into the future of the coming moment. They had to live entirely in the present, in the moment of now – not in the capacity of an observer, but as an agent actively taking responsibility for the Self. The extended present therefore represents that expanse of time that they believe they have shaped or will still shape (Cottle 1976: 173). An essential part of this "shaping" is taking control over their own interpretation of events. Thus, by positioning the Self as an active agent in the extended present, as an agent who has the sovereign power to choose an interpretation, the participants were able to assume greater responsibility for their experience both of illness and of Self.

Thus, my participants experienced profound change at the onset and during the progress of their illness. The character and consequence of this change is particularly pronounced in the case of an illness as notoriously long lasting and variable as ME. The subjective experience of such an illness can be despairingly disempowering. Where a past filled with insecurity and a future brooding with anxiety reside within the present, the ill person suffers. In a sense the content of the sufferer's time perspective – the temporal signs – that govern the interpretation of new events are sculpted by the suffering caused by severe illness.

Yet, my participants had the option to choose to direct their "attention of life" to the extended present. There, the sufferer has the power to choose a perspective from which to view events and appraise the Self. There, the sufferer can make a decision, can consciously choose an interpretation of actual happenings that is supportive of the Self in this moment. There, in the extended present, the sufferer assumes responsibility for the Self and its suffering.

While this approach may appear deceptively simple, it is not. It is not simply a matter of emptying the experience of time in this moment from past and future dimensions. In fact, this cannot be done. For, to experience the present, we must have the memory of the past and the expectation of the future. Time perspective is never an empty space. The extended present, therefore, includes both past and future, but only that portion of past time for which the person feels responsible and only that portion of future time that they believe they can shape and control.

At this point, the experience of illness and Self has become a matter of personal responsibility. In fact, it is now an act of utter *ir*responsibility to dwell on a past-gone-by or cast an anxious glance towards the future-to-come. It is *ir*responsible exactly because it diverts the person's focus away from where the gist of personal responsibility is now located: the extended present. It is, after all, in the extended present that the sufferer must be wholly supportive of the Self-of-now who confronts the challenges of illness. Personal responsibility is here more distinctly than anywhere else defined and lived in present tense.

A person... has a transcendent dimension

Cassell (1991: 43) states that a person "has a transcendent dimension – a life of the spirit, however expressed or known". This is the timeless dimension of personhood, the quality of being greater and more lasting than an individual life, of having meaning and purpose that exceeds the present state of being. This is the final dimension touched by illness.

The transcendent dimension in the lives of the participants in this study was strikingly revealed through their search for the meaning of their suffering, of human suffering. Having had their world "unmade" by the onset of a serious and highly disruptive illness created a need to make sense of the situation – to find a reason, a purpose, or some other form of meaning (Ware 1999: 320). The participants' search for such meaning was resolutely directed towards assigning a meaning, identifying a purpose, detecting a destination... all to make sense of an otherwise incoherent, almost incomprehensible experience of illness. It was a search rendered all the more important in the face of a Self and society evidently equally bereft of a rational explanation and remedy for their illness (cf. Williams 1989: 287).

Natalie expressed many of the participants' search for meaning, for transcendence:

Ek... ek... ek hoop *van harte* dat ek in die toekoms eendag met hierdie siekte iets positiefs sal kan doen en ek hoop ek sal vir iemand iets kan doen en dalk daaroor skryf of iets, ek weet nie... Mmm... dis nogal 'n geloof... iets waarin ek... vorentoe na uitkyk. Ek voel daar *moet* 'n doel wees, daar *moet* 'n plan wees en... mmm... daar *moet* 'n plek wees vir jou lewe. So, ek's... ek... ek probeer maar... ek *probeer* hierdie idee *altyd* vashou dat... op een of ander tyd in my lewe sal ek iets *goeds* vir iemand beteken, *ten minste dit*, jy weet, want dit bly maar vir my *altyd* negatief.

For those confronted by a seriously debilitating illness, meaning is often found in gains in inner strength or personal growth, in the ability to confront longstanding interpersonal

problems or in learning to cope with negative emotions – all as a result of being ill (Ware 1999: 320). For instance, in Kelly and Dickinson's (1997: 261) study, a respondent with a severe chronic condition found meaning in her experience in the greater awareness and acceptance of the Self that had followed as a result of suffering from ulcerative colitis. In a similar way, the quest towards transcendence led Natalie to locate the meaning and purpose of her illness in the greater good. Suffering for the sake of others became the surpassing principle that defined the supreme significance of Natalie's experience of illness. By assigning a greater, a transcendent meaning to the illness, Natalie reduced the suffering associated with it – it now had a purpose; it was part of a plan. In this way transcendence, which located Natalie in a landscape of meaning far larger than her individual Self, offered a powerful means through which to restore her personhood to wholeness (cf. Cassell 1991: 45).

Natalie's account exhibits a further quality of the search for transcendence, namely to find a meaningful interpretation of illness involves narrative reconstruction. Williams (1989: 270) maintains that the explanations advanced by ill persons act as narrative reconstructions of the profound suffering in their daily experience of life in the presence of illness. Their illness becomes part the story of their past as perceived (and construed) in the present. Their story, as an imaginative reconstruction, is therefore not a simple thread consisting of instances related as "when that had happened, then this happened". Instead, through the narrative reconstruction involved in finding transcendence, the past of this present is reconstructed in such a way that the experience of illness and suffering is better understood and the impression is reaffirmed that life has a course and the Self has a purpose. Thus, in construing a particular story, Natalie found significance in the experience of suffering and fortified the belief that through illness her life was indeed purposefully on course to help others. Natalie's story allowed her to be and become whole – despite illness.

Through constructing a story that brought meaning and purpose to her experience of illness and suffering, Natalie assumed the position of author of her own narrative. But this is not always the case, as Cheryl's account suggests. Cheryl's description indeed identifies a different author at work:

... I have been opti... mmm... not optimistic in the secular sense, I've been optimistic in the Christian sense in that I'm convinced God has a plan for my life, I really am convinced, I don't just say it as... words that I've been taught in Sunday school... I am personally convinced that He has a plan for my life and that it will be worked out according to His will... and so that even if that plan includes me not living very long... mmm... it will be according to His will... I can really think back on... these past ten years and possibly the next ten years, who knows... with the thought that it *has* to be for a reason, it *has* to be... it

has to be. And that's not out of some theological handbook or... or textbook, I *genuinely* believe that. If life were random... I think that I would have committed suicide... if it we... if I felt it were random. Or... if I felt I'd fallen into the hands of some demonic force... you know... and there was no shield of God's love protecting me... and that... that for some reason, best known to Him... He decided to step aside and let the... the forces of evil take... hold of my life... *golly*, if I had to believe that I would be *petrified*... But... I've... I have a certainty borne of these last ten year that is *un*shakeable, that there has to be a reason for this, it's *absolutely, utterly unshakeable*.

Cheryl completely believes that God has a plan, a divine reason, for her illness and her suffering. Where an individual life is so wholly entrusted to God, the idea of a separate, vulnerable, personal purpose makes little sense. Although God's plan might at times "appear to us as biological caprice and senseless biographical disruption" (Williams 1989: 285), His purpose prevails – unconditionally. For individuals such as Cheryl who cherish this interpretation of life and illness, God is the ultimate author of their narrative. Consequently, there is nothing, no meaning and no order, for them to reconstruct or explain. In fact, for them, the course and end of their life are defined outside of their own being. For them, "all analytic puzzlement and personal doubt evaporate in the glare of God's purpose" (Williams 1989: 286). Thus, liberated from the burdens of personal narrative reconstruction, Cheryl was able to experience transcendence through the earnest belief in God as the ultimate source and author of meaning – in her life, in her illness and in her suffering.

For the participants in this study, the transcendent dimension of their personhood offered perhaps the most powerful way for them to restore integrity after the injury inflicted by illness. It gave meaning to their otherwise incomprehensible suffering, purpose and significance far larger than the Self, than the individual person, and hence it brought relief. Whether they chose to write their own story of the past to give meaning to the present or whether they relinquished the rights of authorship to a God, their quest towards transcendence undoubtedly represented a profoundly spiritual experience. Indeed, through its timeless, transpersonal quality their quest stretched beyond the limits of person-circumscribed experience and reason. Their quest reached out and gained supreme transcendency.

Conclusion

When an illness as intense and severe as ME sets in, the personhood of the ill changes *profoundly*. It is change so immense that no dimension of personhood is left untouched or unscathed. When confronted by change so incredibly foreign to the Self-who-was, the Self-of-

now, the ill Self, experiences a tormenting scourge of insecurity, uncertainty, instability, and insufficiency. The intactness of the person ruptures. Inner integrity falters, wavers, staggers, and threatens to deteriorate into complete non-being. This – the very real threat to the wholeness of personhood, the impending diminution of being – defines the actual nature of suffering as endured by the ill in this study.

What then would bring relief to such a dire state of suffering? As suffering very clearly causes a disrupted personhood, any endeavour to relieve suffering strongly relies on a reconstruction of personhood that firmly secures inner integrity. Such a "re-constituting response" involves the ill person as an agent acting directly in and on her social world (cf. Ware 1999: 318). These actions attest to one of two intentions. On the one hand, the ill person seeks to preserve the everyday lifeworld as it existed prior to the onset of illness. The participants indeed desperately wanted to preserve and maintain their former Self, their "old Self". On the other hand, the ill person seeks to re-make that world in ways that allow for continued ("normal") participation in social life. Participants were keenly aware of the need to reassemble the different dimensions of their personhood to allow the expression of a "new Self". Yet, the fact that the latter was only truly possible at the expense of the "old Self" made the struggle to adjust successfully all the more difficult. To relinquish one intimately known Self intentionally in favour of another as yet alien entity was no simple matter. As a result, the inner battle to re-establish integrity raged intensely.

The resolution of this conflict, the ill person's ultimate response to the demand to adjust, determines the degree of suffering... *and* the fate of the sufferer.

Suffering *continues* unabated when adjustment is obstinately resisted. The "old Self" desperately strives to cling to the "normal" existence enjoyed by the Self-before-illness. Despite change, despite the very real loss of former abilities and capacities, the Self desperately tries to hold on to what was at one time certain, secure and known. Unfortunately, this inevitably futile struggle to give expression to an old Self who can no longer be negates any possibility for the reconstruction of the person, of a new, whole Self. Hence, as the struggle persists, inner conflict continues, and so too does the suffering.

Suffering *recedes* when the sufferer pays heed to the call to adjust. Such adjustment reflects the sufferer's strategies to live with a medicated body that is spatially and socially positioned and confined by cultural norms, expectations and responsibilities. Within this context,

adjustment means embracing a "new Self" – an undertaking that constitutes the desired option not simply when the need for a reconstructed whole person is acknowledged. Rather, it becomes the desired option only when this acknowledgement is accompanied by the realisation that the power to create such wholeness lies *within the Self*. At this point, suffering becomes a matter of personal responsibility, a matter of choice.

Within this context, personal responsibility as embraced by the ill assumes a very specific definition. It is now an act of utter *ir*responsibility to dwell on the past as this simply invokes self-blame for becoming so ill, for taking so long to recover, for struggling so badly to cope. This is *ir*responsible for it diverts the sufferer's focus from the present where the core of personal responsibility is now located. Personal responsibility demands the sufferer to be wholly supportive of the Self who confronts the challenges of illness in this present. In other words, personal responsibility no longer has a retrospective, punitive focus; instead it is here and now, defined and experienced in the present tense (cf. Collinge 1993: 126-130; Totman 1990: 117 & 171).

Shouldering such personal responsibility involves the deliberate exercise of personal choice. Indeed, to maintain a focus on the now requires a conscious decision to arrest the flow of time in this moment. In this moment, the past of this present can be imaginatively reconstructed to impute meaning to the lived history of the Self-who-was. In this moment, the interpretation of actual happenings can be determined to support and empower the Self-of-now. In this moment, the Self-to-come can be judged to be purposefully on course. This moment, this instant of self-reflection, therefore, both constitutes and permits a conscious decision to reconstruct and recreate a whole person. It is a conscious decision to alleviate suffering.

The conflict between the old Self and the new Self, between struggle and adjustment, between past and present, between disruption and wholeness, between suffering and integrity, fills each moment in time. It is a choice that is made over and over again, every moment anew. Every time the responsibility for the Self and its suffering weighs down the sufferer. Every time, the power to choose presents itself. Every time, the decision to accept responsibility and to make a choice *belongs to the sufferer*.

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Summary

The human reality of ME sufferers essentially revolves around their subjective experience of suffering, an experience that is infinitely influenced by those whom they meet on the road to wellness. As they travel along this road, they reconstruct their world and themselves around their illness, forever mindful of their supreme desire to live as normally as possible.

To prosper on this road to wellness, ME sufferers yearn to experience a sense of understanding from those whom they encounter on this journey – the medical practitioner, the family member, the friend, the acquaintance. They desperately want their illness and their experience thereof to be understood by those they meet. If complete understanding proves too difficult to muster then a simple, unconditional acceptance of their experience of illness, of their reality, would suffice. This acceptance should ideally be accompanied by an open acknowledgement of the fact that human suffering inevitably influences the ill person as a whole; that with the onset of their illness, their needs, their abilities, their interests, their very ideals changed. They changed, profoundly.

Yet, along ME sufferers' road to wellness a demon roams wildly. It is the demon notorious for its huge capacity for ignorance. From the medical specialist to the mere acquaintance, at each level of human existence, sufferers have been confronted by this demon. As it grumbles in the darkness of its own ignorance, it reacts to the illness experience of unsuspecting ME sufferers by denying the existence of their illness. It denies the legitimacy of their illness. It denies their very experience of reality. Perhaps this demon is a manifestation of society's failure of knowledge and understanding... or perhaps it is more truly a failure of simple humanity itself.

Through its response to ME, the demon of ignorance inspires a cruel stigmatisation of both the illness and of those who claim to suffer from it. In turn, this reaction adversely affects sufferers' concept of Self, of identity. Indeed, any humane construction of the Self is effectively undermined by sufferers' recurrent experience of failing and failure as they become aware – and are made aware – of their inability to meet their own and society's standards and role demands in the different contexts of interaction. ME sufferers are, in short, simply too ill to live up to what society expects from its members. Hence, they eventually begin to feel deficient, incomplete, and incompetent.

Therefore, ME sufferers' experience of "deficiency", of a spoiled identity, seems to result from a conflict raging between society and the sick person. On the one hand, the sick person wants to be understood and desperately longs to be part of "normal" society – but miserably fails to be. Society, on the other hand, understands neither the illness nor the ill person and, hence, opts to distance itself from the sick. This conflict is surely dreadful enough to maim many who experience illness and suffering. Still, this is not the whole truth.

The ill person, the ME sufferer, is inclined to locate the conflict experienced outside the Self. Doesn't it, after all, lie in the standards and rules determined by society? Isn't the very origin of the apparent conflict then situated in society itself? Although this might appear to be the case at first glance, it is not. In fact, the "standards and rules determined by society" that appear to cause such hardship and anguish among the ill, reside within the ill themselves. In other words, the social standards that the ill person strives to comply with appear to be external, but are indeed internal, although they are admittedly continually reinforced and re-interpreted externally. The social requirements, the rules for behaviour and expectations of the world of others are, as Cassell (1991: 53-63) explains, contained within verbal categories such as "patient", or "pain", or "disability". The content, the very meaning, of these and other such verbal categories is contained within the ill person. The fact that they are shared with others, from the general practitioner to the journalist, creates the illusion that the standards of daily action, rules for behaviour, requirements and expectations are all external. This is, however, a fabrication of the mind. Thus, as the ideas and beliefs – indeed, all the content of social categories – are contained within the person, it follows that the origin of the conflict cannot possibly lie in society or, for that matter, solely in any disturbance between society and the sick person.

Instead, conflict for the ill person is very firmly located within the ill person's Self. It is an internal conflict, a self-conflict (cf. Cassell 1991: 53-63). It is a conflict that blazes between two competing needs. On the one hand, sufferers need to feel accepted and valued. They want to be and forever keep trying to be part of society. They need family, friends, associates and acquaintances to be a complete Self, to be fully human. On the other hand, in their efforts to be part of society, they are faced with false accusations, ridicule and judgements, not to mention their own inability to achieve the standards and expectations entailed in daily living. Therefore, it is little wonder that they experience a desperate but simultaneously contradictory need to retreat and protect the Self. They want to withdraw to the safety of a private world to avoid the physical and emotional pain and humiliation which confront them in the public

world. This is the internal conflict which rages desperately between the desire to live in society and the need to retreat from it.

What then is the solution to this conflict? Where does the answer lie? Does it perhaps demand some transformation, an alternation, a shift in society or in the ill?

The solution to the conflict lies where the conflict lies: in the ill person's Self. It is the sick who must learn, above all, to live with themselves and to continue, as normally as possible, on their journey to wellness. To do this, they are required to rewrite the rules and requirements of society for themselves, guided by their own interest and capacities. For ME sufferers this challenge involves the development of a deeper awareness of Self, accompanied by a stronger belief in the Self and in the authenticity of their own reality as they perceive it. The sufferers become more self-reliant and assume – or very often re-assume – the right to govern the Self, to be fully in charge of the Self. Even more importantly, this dynamic process also comprises the discovery of choice as the sufferer re-learns that personal experience and the essence of interaction do fall under personal control. Furthermore, through the power of personal choice, sufferers are not only enabled to act on their own behalf and in their own best interests, but also to fully embrace personal responsibility. Ultimately, despite all the odds, it is the sufferer's responsibility to protect and take care of the Self, to be the Self to the fullest possible extent possible, there where life is lived.

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PART V

Introduction

When we, as social researchers, attempt to do justice to a social reality under study, we offer a particular way of understanding that reality, we develop and present a theory. The value of this theory is exclusively defined neither by the science and scientific procedures through which it has been constituted nor by its compliance with the canons of objectivity governing so-called rational inquiry. Instead, the value of a theory is also *firmly situated in the opportunity it presents of escaping ignorance through alternative ways of seeing and perceiving. In following this tradition, I present a description, a theory, of the experiences related by those ME sufferers who chose to disclose their social reality to me. But wherein lies the value of this theory, my theory?*

Any assessment of the value of my theory must be based on a recognition that my story does not represent the "closest approximation to the truth", let alone a direct disclosure (or perfect mirror image) of it. This would after all, as I have shown, presume the existence of an absolute point to which all theory can be compared – a presumption I have clearly rejected. For me, all social science theory – including my story – is better regarded as a human construction – presented by a particular human researcher who is explicitly present and identifiable throughout its development. That is, I – the researcher and the theoriser – was (and still am) directly involved in the entire research process. I am forever contributing to what is told and how it is presented – also now. The researching I cannot be ignored or omitted. Hence, just as I am bound to do justice to the social reality under study, so am I bound to render an accounting of the ways in which I have attempted to do so.

This contention does not mean that any determination of the actual value of my story necessarily has to assume the form of free (unbridled, undisciplined) indulgence into the nature of my own presence and existence. Instead, I will aim to present in Part V an exact and rigorous description of my own presence throughout the research process. You, the reader, will see me as I was actively involved throughout the research process. You will become acquainted with me, the human researcher. And as you do, you will (ideally) be able to identify my contribution, my perspective, in the story that I told (and am still telling now). You will become familiar with my very acts of understanding, with the grounds of my knowledge. In post-modern terms, you will become equipped to deconstruct what I have constructed.

To offer such critical insight into my presence and contribution, I will focus in Part V on the very acts of research by exploring the implications and repercussions of the methodological approach I had followed in this study. What was my experience of the methods I had used? How did my participants experience them? In what ways did it influence our relationship? How did our encounters influence me? And how did the methods I chose and my relationship with participants influence the story I was eventually able to tell? Throughout, I will seek to meet the challenge posed in Part II – to free my knowledge through the disciplined practice of critical reflection.

Chapter 17
Dismantling the power relationship

"Research involving people with the diagnosis of an incurable condition offers a particularly charged scenario for the researcher. When that condition is being lived within a social context of stigma and marginalisation, we have a responsibility to consider the politics of research" (Small 1998: 127).

Small made this comment in the context of HIV/AIDS, but his argument is equally applicable to this study on the subjective illness experience associated with ME. This realisation calls for a consideration of the ways in which the research process and specific research procedures impacted on the power differentials within the research context. How far did my approach go in furthering the ideals of equity and equality in research? Or did it simply work to reproduce existing power relationships?

In this chapter I will illustrate the difficulties I faced in attempting to realise the ideals concerning equity and equality when entering social fields structured by competing and conflicting interests, perspectives and expectations. I explore the extent to which this is actually possible and suggest that, despite good intentions and the desire to facilitate an equal relationship, as a researcher I operated in a context where such research contracts are rendered very hard to realise, if not impossible.

The academic legacy

Heaphy (1998: 31) acknowledges that the academic disciplines in which we operate play a crucial role in defining the appropriate methodological approach. In this sense, our academic legacy plays a critical part in defining the research relationships through which we do research.

For the most part, the social sciences are marked by the legacy of positivist thought and objectivity. Within the positivist canon of belief on objectivity there is, according to Stanley and Wise (1983: 194), a sanctification of an asymmetrical power relationship between the researcher and the researched. Positivism sees the researcher as the "expert" – as more competent because he or she is more "objective" – in understanding other people's lives better

than are the people who live them. Here, objective knowledge is regarded as consisting of general mental representations which obtain their meanings exclusively through their capacity to correspond to the external world. Objective knowledge representing real world events has priority over personal experience in which representation of inner states cannot be excluded (Heaphy 1998: 31). Thus, the ability to discern reality "objectively" becomes the prerogative of "the scientific mind" that is trained and operates within a scientific ethic which "insists on the scrupulous removal of commitment and value" (Stanley and Wise 1983: 194). And since research participants – the "objects" of study – cannot equally rid themselves of their own subjectivity they are regarded as "less competent" in discerning reality objectively. They are therefore relegated to the subordinate position of "respondents" - a telling name (Oakley 1981: 35).

In recent years, the positivist approach to research relationships has increasingly come under attack – and perhaps more so (and more directly so) by the feminist tradition than by any other school of thought. In contrast to the sanctification of unequal power relations, feminism urges researchers to endeavour to dismantle the power relationship that exists within the research context. According to the feminist tradition it is after all, as Stanley and Wise (1993: 168) write, both "obscene" and "morally unjustifiably" to treat people as mere "objects" there for the so-called "expert" researcher to do research *on*. Feminism thus poses a direct challenge to the conventional and characteristically positivist view of the research relationship.

According to Briggs (1996: 10-11) feminist attempts to counter the positivist conception of an asymmetrical relationship of power within the research context have often coincided with attempts to unify the researcher and the researched through an emphasis on "a common humanity". Briggs, for instance, shows that some feminist researchers, such as Oakley (1981), do not discuss the existence, let alone the influence, of any differences of power or privilege between them and their participants. For these researchers who ardently attempt to push away or ignore the reality of power which permeates the research context, the potential influence of such differences appears to be rendered insignificant in the presence of "a common humanity" that is usually promoted under the banner of "sisterhood".

In contrast, Bloom (1997: 118-119) writes that while researchers, and perhaps feminist researchers in particular, may feel or wish to feel some connection of a more or less intimate nature with their participants, it is crucial not to "bury the differences of our social relations under an idealistic façade" of sisterhood. Instead, it is necessary to maintain a realistic attitude

towards the research relationship, recognising "sisterhood" as a "fortunate outcome of some projects rather than a precondition of all research relationships" (Reinharz in Bloom 1997: 119). Sisterhood should, therefore, "neither be idealised as nor equated with a state of... universal sameness" as this will only serve to obscure profound differences of power within the research context and, hence, leave the power that inevitably positions both the researcher and the researched invisible, unacknowledged and indeed unchallenged.

Thus, while recognising the need to steer away from the asymmetrical conception of research relationships as conceived of in the positive tradition, a denial – or disguise – of such power relations within the research context will not suffice. Rather, "we must", as Wise (in Ribbens 1989: 590) advises, "acknowledge power where it exists and learn to deal with it wisely". We must recognise the process of research – the very process of knowing – as a political one – the results of which are directly shaped and influenced by the positioning of both the researcher and the research participants (Heaphy 1998: 21-25).

Once recognised, it becomes critical to assess and clearly explicate the central part played by the researcher in constructing the research context and research relationships. In support, Stanley and Wise (1993: 168) advocate a research approach that will "lay open" and "make vulnerable the researcher" by rendering the researcher's conduct, reasoning and evidence available for scrutiny by others. This represents a very serious concern with making explicit not only *what* the research understands about the phenomenon of interest, but also *how* he or she has achieved this understanding. Because I share this concern I will, in the remainder of this chapter, reveal my own construction of the relational (political) context as well as the more (and less) subtle influences of positivist and feminist teachings on both myself and the research participants.

The "why" behind research

In line with a growing emphasis on the need for more reflexive approaches to research, the profession is recognising that the results of research are shaped and influenced by the positioning of the researcher. This positioning, together with the context of research, works to construct particular truths on any given topic (cf. Heaphy 1998: 21-22). A critical dimension of this positioning is the researcher's motivation to embark on a specific study.

Heaphy (1998: 31) notes that, in terms of the motives of research, the notion of the "pure" researcher who is unaffected by his or her social, cultural and political positioning has been widely challenged. According to Heaphy (1998: 31), it has been suggested that most research is generated by a series of circumstances relating to the particular researcher and the economic, social and political context in which he or she works. In this way, the personal interests and skills of the researcher meld (often mysteriously) with a broad range of professional and political motives to determine a particular research topic.

The complexity introduced by such an amalgamation of motives even more strongly emphasises the need not only to reveal how, but also why, research was conducted. Where we fail to do this, Heaphy (1998: 31) says, the illusion of objectivity remains intact. For Heaphy (1998: 32) this is to "become actively involved in the reproduction of knowledge-power relations in a way that is at odds with the possibilities offered by reflexivity". At its most radical point, what is at stake here is not simply a reflection on the history of a project, but rather an attempt to *reveal* the project as it happened – including the researcher's motives (Heaphy 1998: 32).

> Within the broader context of ME research, it is almost as though researchers active in this field assume – at least to some extent – a common agenda, whereby the personal impetus behind a project almost goes without saying. Yet, because this is not necessarily the case, and because others might not necessarily share the assumedly implicit notion of integrity and worthiness, the motive behind any research project – this one included – must be clearly explicated. In this study, as is typical in most ME research, the "why" is answered by reference to the "urgency" of the "crisis" of ME. Yet, in this study, the contribution to this "common" cause has been articulated specifically in terms of the importance of developing a better understanding of the illness to so (perhaps) contribute towards greater recognition of the experiences of those who suffer from ME.

Heaphy (1998: 32) furthermore maintains that an explication of the researcher's motives becomes even more critical where we "research ourselves" – that is, where the social world under investigation hits very close to home. We must then "interrogate and reveal our own motivations, not least of all in terms of who the research is strategic for" – the individual researcher or ME sufferers generally (Heaphy 1998: 32).

> With regard to my own work, this instruction has evolved into an exploration of questions such as: To what extent is the focus on the changes experienced by participants an indication of my own interest in such changes? Is the focus on the meanings and personal implications of ME related to my own negotiation of the meaning of the illness? Does the concern with personal stories reflect my concern with my own story? And would this make the research autobiographical to any degree?

It is often implied that researching a topic so close to home, a topic that would put the researcher entirely centre stage, would nullify all attempts to be "neutral". Such a perspective, though, plays right into the dynamics related to the notion of objectivity referred to above. While the motives for researching "ourselves" as ME sufferers do not go without saying, the position of non-ME sufferers conducting research in this field is (after all) *equally* problematic. Following Heaphy (1998: 32), I argue that unlike the claim to be a feminist researcher – which reveals an alignment to a broader "political" project, even if there is by no means broad agreement on what that might mean – the label of ME researcher reveals very little. It tells us very little about the researcher's personal or political project and how it has influenced what, how and why he or she does what he or she is doing.

Thus, irrespective of our status as ME sufferers, it is in revealing "our Selves" that we as researchers can begin to demonstrate awareness of our personal involvement in the research context. In doing so, we may also become able to better comprehend (and reveal) the political implications of such involvement.

Putting the structure in place

The "expert" status ascribed to social researchers within the positivist tradition represents a principal foundation of their power in the research context. By accepting a position of superior expertise (whether consciously or unconsciously), researchers assume the power to define and take charge of the research process in their own terms and in line with their own values and norms (Kelman 1972: 991). Mishler (1986: 122), for instance, writes that within the context of data collection, participants are often presented with a predetermined scheme of relevance. In other words, the different research questions and related areas of interest are all introduced,

framed and specified by the researcher. In addition, it is the researcher who assumes the power to determine the adequacy and appropriateness of participants' responses to inquiries. This configuration of power in the research context clearly places the research participants at a disadvantage.

While this argument carries some merit, it is certainly one-sided. Participants too have considerable power to structure the research context. The researcher's ability to carry out a specific study after all ultimately depends upon the participants' cooperation. In this regard one must acknowledge, as Cotterill (1992: 599) and Kelman (1972: 992) do, that participants have the option to withdraw from a study or to undermine a project by providing false information, performing a required task improperly, or engaging in some form of subtle sabotage. Oakley (1981: 56) even goes so far as to say that participants are "people with considerable potential for sabotaging the attempt to research them".

Despite this potential for resistance and even sabotage, participants rarely use their power. According to Kelman (1972: 992), one culprit here is the powerful "expert" status that the positivist approach confers upon the researcher. This status appears to discourage research participants from exercising their potential power within the research context. Kelman (1972: 992) explains that participants tend to feel that they lack the capacity to question research procedures because they do not have the necessary expertise and specialised knowledge to do so. In turn, the researcher's apparently superior informational base is an important component of his or her legitimacy in the eyes of the participants. That is, the researcher's expertness contributes to the participants' view that he or she has the right to set the rules and prescribe behaviour in the research situation. Kelman (1972: 993) notes that this perception that the "expert" researcher is legitimately in power is further encouraged by the value that society accords to "science". This value impels participants to feel obligated to cooperate and reluctant to question procedures that are presented to them "in the name of science". Thus, when participants accept the legitimacy of the researcher and the authority of science, they become reluctant to claim the right to question procedures, let alone the legitimacy of the researcher's relative power over them.

In this study my relative position of power was never directly questioned in the research relationship. Yet, this did not leave me any less vulnerable. While I could never expect participants to proclaim a similar commitment as my own to the study, the progress of the study was very much dependent on exactly such a commitment from their side (cf. Cotterill 1992: 602-603). And given their unique circumstances, it often became clear (at least to me) that my study did not necessarily carry the largest weight in terms of priority. This point was evident on a number of occasions:

> My own sense of vulnerability was emphasised through my experiences with Natalie and Denise. Once I had secured Natalie's cooperation, we set about scheduling our first meeting without too much difficulty – that is until a couple of days before our appointment. Natalie had suddenly become very ill, was bedridden and certainly in no condition for an interview. Nearly a month later we were still trying to arrange a first interview. Not only had she still not recovered from the most recent relapse, but her studies were also demanding what little energy she had left. My study was not at the top of her list. Similarly, on the morning of my first interview with Denise, a friend of hers called to say that Denise had been admitted to a special clinic that very morning. Denise only returned to her home (and so once again became available for an interview) almost two months after our first appointment had initially been scheduled to take place. My study could obviously not contend with Denise's state of health and the possibility of treatment in a special clinic.

Thus, even where participants do not intentionally question the researcher's power, their circumstances might not allow them to remain consistently committed to the study. And where this happens, the researcher clearly has access to very few sanctions. The relative powerlessness of the researcher is further reinforced by the etiquette of the interview itself. This generally forbids even the most self-disclosing interviewer from being openly judgemental about a participant. There may thus be situations, as Lee (1993: 110) notes, that the researcher simply has to endure with gritted teeth.

It is furthermore often emphasised that it is entirely up to the researcher to instil and sustain an adequate level of commitment among participants to ensure that the study develops beyond a set of unexplored hypotheses (cf. Cotterill 1992: 602-603). However my study shows that

such control does not always lie in the hands of the researcher. Far from being in control, the researcher may at times be exceptionally vulnerable:

> At the end of the first interview, participants were introduced to the autobiographical sketch. Each participant left the interview armed with a guideline for the sketch, promising to complete the sketch within three weeks, give and take a couple of days. Yet, this task turned out to be far more demanding than I had anticipated. Participants such as Natalie found it difficult – indeed impossible – to complete the task within a reasonable period of time. After many telephone conversations and many apologies, her sketch was only ready three months after the initial request – this despite my best efforts to be as accommodating and supportive as possible. This situation was unfortunately not limited to one participant. Cheryl too struggled. While putting in a tremendous effort, and even deliberately conserving her mental abilities while working on this task, the sheer effort still took its toll. Physically, it was often just too painful and toilsome to write for any extended period of time. And mentally, her abilities quivered under the demands of this task. A struggle it then certainly was – for my participants and for me.

Circumstances such as these cannot be foreseen. Worse yet, there is very little a researcher can do to tame the effects it might have (will have) on the progress of the study. Researchers' very dependence on their participants renders them largely powerless in the face of such circumstances – and, I would add, particularly in the face of severe human suffering.

Thus, the study of sensitive topics has implications for the power of both the researcher and the researched. Within this context, power is exerted by both the researcher and the participants in terms of the structure and procedures of the research setting. And while both parties have, in theory, access to considerable power, the means through which to exercise this in practice are not necessarily easily – and certainly not equally – accessible.

Moving towards greater interaction

Stanley and Wise (1993: 168) indicate that feminists have sought to confront the disproportionate distribution of power within the research relationship by rejecting "research on" in favour of "research with", thereby indicating a preference for more interactive research

approaches. For feminist researchers a better way of finding out about people's lives is to make the research endeavour a more interactive experience.

An interactive research approach, as described by Laslett and Rapoport (1975: 968-973), attempts to engage both the researcher and the research participants in the research process as a joint enterprise. The research relationship is accordingly defined as more mutual, less hierarchical, and decidedly non-manipulative. These characteristics of the research relationship reflect a strong emphasis on the more active involvement of the research participants in the research process. Such involvement represents the means through which the difference of power that permeates the research context can be addressed.

Participatory research, a similar though more comprehensive approach, also stresses the value of "authentic involvement" (Mouton 1996: 36) on the part of the research participants. Mouton (1996: 36) shows that, within this approach, research participants are regarded as "equal partners" and are encouraged to become active members of the research team. They are indeed called upon to participate in both the design and the execution of the research process. In turn, the researcher is expected to become an active member of the community under study. The active, committed and ideally equal involvement of both the researcher and the research participants represents contribution by participatory research towards equalising the balance of power within the research process.

Both of these approaches attempt to generate a collaborative approach to the research endeavour that engages both the researcher and the participants in a joint enterprise. These approaches go some way in rejecting the objectivity-based principal of hierarchical relationship between interviewer and respondent. And, perhaps more importantly, they also promote patterns of research that would avoid the misuse – or arbitrary use – of power by researchers (Kelman 1972: 1003).

Such approaches are typically associated more closely with in-depth qualitative research than more structured quantitative studies. Both Brannen (1988: 555) and Opie (1992: 64-65) confirm that, unlike more rigidly specified research projects, in-depth research provides considerable opportunity for participants to become involved in the research process. Participants are placed in a position of control over both the nature and content of the research interaction and the data it generates. Moreover, such research also empowers participants as it

works from the assumption that these participants can contribute significantly to the description and analysis of a particular social issue.

> In this study interviews were guided by a schedule broadly listing a number of areas I had hoped to cover during my conversations with participants. However, because I was aware of the influence of the researcher, I was concerned about the extent to which these "pre-specified" focus areas would influence what participants said about certain aspects of their experience – to the exclusion of others. In other words, were the interviews in some way "set up" by my Self? Or did it allow for the involvement of participants? It was then with relief that I soon discovered that my conversations with participants easily turned into a participant-led endeavour. Participants talked about the issues that were most important to them – not simply as dictated by me or by my schedule. This gave rise to a great deal of information that had not been anticipated. It also pointed to the strength of the semi-structured in-depth interview that allows for more interactive involvement by granting participants more control over the content of interaction and indeed over the interaction itself.

In this study, then, a more interactive, less structured approach worked towards establishing a more equal distribution of power within the research relationship. Participants' contributions were valued as significant – and perhaps especially so as they gave a voice to a silenced and dearly misunderstood group – a voice that may serve to question directly several established (mis-)conceptions concerning ME and the ME sufferer. In this way, the more interactive research experience may, as Opie (1992: 64-65) observes, indeed be a very empowering one.

Thus, where the format of the research is not rigidly specific by prior standardisation, it is possible to see the exercise of power in the interview as a two way process – as exerted by both the researcher and the researched. Yet, as it will become evident in the next section, this exercise of power is limited by participants' expectations of the research process. It is specifically the extent to which traditional notions of objectivity have influenced both researchers and the public (that is, the research participants) which should not be underestimated.

Disparity in disclosure

Within the research context, the discrepancy in power reflects an asymmetrical distribution of rights and obligations – and in particular, a disparity of disclosure rights. The researcher may obtain revelations (and often deeply personal ones) from the participants, but need not reveal anything in return. Despite admonitions in the literature to establish "rapport" with the participant, this disparity of rights between researcher and researched gives that rapport a spurious and ultimately instrumental character. Consequently, social research might be perceived as operating in an oppressive way which mirrors (or even promotes) wider patterns of social inequality (Lee 1993: 108).

For these reasons writers like Oakley (1981: 49) insist – as a matter of ethical commitment – on a style of research based on reciprocity and a process of mutual self-revelation. Oakley (1981: 41) indeed believes that the goal of finding out about people is best achieved when the researcher is prepared to invest his or her own personal identity into the research relationship. For Oakley (1981: 49) such an investment is best achieved through (and supported by) the rule of "no intimacy without reciprocity". In other words, contrary to traditional teaching which emphasise research by the objective external scientific mind, Oakley places the focus directly on the quality of the research relationship itself. She acknowledges that gaining and maintaining satisfactory participation within the research context is never the primary objective. Yet, it is so intimately related to the quality of the information sought that the researcher is urged to always maintain a dual concern: not only for the quality of the information sought, but also for the quality of the participant's experience.

> By early 2000, my study had suffered a number of delays. I had been very ill and it had taken much longer than expected to receive participants' autobiographical sketches. All of this prevented me from proceeding as planned and as agreed initially with all participants. Given this, and bearing Oakley's advice in mind, I felt it necessary to contact each participant to explain the situation and to re-affirm their participation in this study. My first call was to Cheryl. During our conversation I found it difficult to explain my situation to her. Time and again her response to my attempts at explanation (let alone elaboration) served to highlight my role as the researcher-who-listens. This reminded me of the "unspoken research contract" according to which the researcher is bound to listen, while the respondent can expect to be listened to (almost unconditionally and certainly without any obligation to listen to the researcher). The second – and very different – call was to Denise. Denise gave me the opportunity to explain the situation and while this left me feeling rather exposed, the honesty of doing so had somehow given Denise the confidence to share her own experiences more openly as well. That is, the open and expressive way in which I had related my situation may very well have positively influenced Denise to feel freer and more confident to discuss her personal situation with me.

Oakley's rule of "no intimacy without reciprocity" is typically associated with the researcher's response to direct questions put by the participants. Yet, in the example above, reciprocity has much more to do with the extent to which the researcher should (is allowed to) take the initiative in sharing personal information with the participant without waiting to be asked. It is in fact a question of whether the researcher is (should be) expected to undertake the same risks of self-exposure as asked of the participants (Ribbens 1989: 584).

Guidance on this question is as varied as the studies conducted by social researchers. Ribbens (1989: 583-584), for instance, warns researchers not to carry out good-intentioned and seemingly harmless offers of reciprocity uncritically. In this regard Bloom's (1997: 112-116) study is a good example. Despite direct offers to tell participants more about herself, such reciprocity was not accepted universally. As some participants viewed the research encounter as an "obligation" or an "assignment", they had very little interest in any personal information the good-intentioned researcher was willing to share. In this sense, Bloom's experience is similar to my encounter with Cheryl. Yet, others such as Smaling (1995: 27-28) employ the phrase "openness of heart" to suggest that by being openly expressive about his or her own situation, the researcher can inspire participants to be more confident and forthcoming in

discussing their own personal experiences. This is then what appeared to have transpired in my conversation with Denise.

The responses to my attempts at reciprocity appear contradictory and even confusing. Yet, upon closer investigation, my experience appears to confirm Ribbens' (1989: 584) advice to researchers to take their cue from the person on the other side of the research encounter. In other words, when questions of a personal nature are posed to the researcher, the researcher should be prepared to answer such questions. Yet, if no questions are asked it is doubtful whether the researcher should nevertheless volunteer personal information. And where it seems necessary to do so, the researcher should remain sensitive to the participant's response and refrain from imposing such "reciprocity" where clearly unwelcome. The participant may after all see such an act as a breach of the "research contract" which gives the respondent the right to talk at length about his or her own life – without being obliged to get to know the listener any better at all.

Based on this understanding it is evident that reciprocity and mutual self-revelation is not, as Oakley and other feminist researchers appear to believe, necessarily the ideal means of equalising research relationships. Cheryl's response in particular makes it clear that this approach might indeed be very limited. Here it appears to be the claim to objectivity that limits the extent to which the research relationship can be (become) an equal one – if only in terms of self-disclosure. In research, the claim to objectivity can work to *silence* researchers in a way that is at odds with the empowering possibilities of a more "equal" exchange of information. This, as Heaphy (1998: 33) explains, has to do with the extent to which traditional notions of objectivity are publicly represented as the defining element of science and good scholarship. As such, they inform not only the researcher's notions of acceptable practice, but also those of research participants. That is, in the research encounter, both the discipline *and* the participants may expect that the researcher's objectivity be manifest in his or her silence.

During the field work phase of my research I experienced that the concept of "objectivity" made it difficult for me to establish the extent to which I could acceptably engage "as an equal" with participants. In particular, tensions arose with regard to ME treatment stories. Some participants showed an uncritical faith in the effectiveness of particular treatment strategies. Very often, such strategies were challenged in other participants' accounts, and in my own experience. For me, reliance on specific treatments seemed based on a false image of the medical profession and its capabilities. Yet, while I strongly disagreed with this, the imperative *not to* influence participants' stories by interjecting (or worse yet imposing) my personal experience and convictions worked powerfully to silence me. In addition, problematising a participant's faith in specific treatments (on which she may rely both medically and psychologically) seemed ethically highly questionable. This tension between disclosing my own opinions and experiences and the (instilled) impulse to remain silent marked much of my interaction with participants.

My research experience shows that it is important to remain aware that when participants such as the ME sufferers in this study agree to be researched, they rarely expect an "equal" conversation or dialogue. While researchers may conceptualise the research process as a chance for "equal" exchange, participants' expectations of the process may, for instance, not include their own accounts being questioned. Here, "we are dealing not only with the extent to which researchers internalise the requirements of objectivity, the question for knowledge, and the assumptions about the necessity of disparities in power between researchers and the researched and the ways in which this is used to justify silence and non-intervention. We must also", Heaphy (1998: 33) urges, "recognise the importance of respondents' assumptions about researchers' silences and what these reveal" with regard to their own decisions and practices.

Thus, while we as researchers and academics might have deconstructed traditional notions of objectivity, this is not necessarily the case for participants. Participants may indeed still retain and value the publicly portrayed ideal of objectivity along with the image it conjures of the sufficiently distanced scientifically minded researcher. The extent to which research participants still value such notions represents important limitations to the ideal of equality in disclosure within the research context.

Power over product

Cotterill (1992: 904) and Ribbens (1989: 587-589) conclude that the final shift in power between researcher and researched is balanced in favour of the researcher exactly because it is the researcher who eventually leaves the interview to assume sole responsibility for the final analysis and interpretation of the data. From this point onwards, research participants are vulnerable.

Bourne's (1998: 98) discussion emphasises the magnitude of the researcher's responsibility in terms of the research product. This author explains that confidentiality – at least within the context of a one-to-one interview – is negotiated with individuals, and "by virtue of our data gathering, we become keepers of 'secrets' and private feelings of an anonymised group or collectivity. We also thus assume responsibility with respect of divulging these 'aggregated secrets' in public arenas". Indeed, the feeding back of such anonymised findings to relevant decision-makers may form part of our negotiated research bargains with participants. Still, deciding which aspects of participants' "secrets" to present is, as Bourne (1998: 98) emphasises, far from straightforward.

Bourne's view of the researcher's responsibility is echoed in Small's (1998: 128) conception of the research participants' contribution as a "gift". By giving their story to the researcher it in a sense transforms the researcher into "a conduit" to pass on what this gift had taught him or her to the world outside the immediate research context. It is a gift "given in good faith" in which the giver – and this is important – is "in no real position to evaluate the potential gains, or to consider possible losses, to themselves or to others". It is solely based on "trust in the judgement of the researcher" (Small 1998: 128). In other words, the researcher is endowed with the (almost exclusive) power (and the burden) to use the gift – the story – to the benefit of others – as he or she sees fit.

The responsibility conferred upon the researcher, when seen in this light, is clearly problematic as it situates the research participants in a highly vulnerable position. The researcher has power over the individual participant by possessing deeply personal and even potentially damaging information which was revealed during the research process. Where such information is revealed in ways contrary to their best interests it might leave participants open to further harm and exploitation (Brannen 198: 555 & 561). Participants may furthermore also be vulnerable collectively since they have very little control over the ways in which the data is interpreted by the researcher. The researcher is after all telling a story from a specific

perspective – a perspective that can quite radically influence the interpretation presented to the world (cf. Small 1998: 139). For instance, a researcher who clearly seeks to promote the interest of (or writes in sympathy with) the researched, may put the research enterprise itself at risk. Such an approach would after all risk romanticising a group of people, or favouring the voices of some at the expense of others. In other words, who is to say that the researcher is a worthy and reliable conduit of the "gift" given to him or her "in good faith" by the research participants? In those cases where researchers turn out not to be a reliable conduit, they almost invariably become a disappointment – or worse yet, a menace – to the people they are studying.

The vulnerability – or relative powerlessness – of research participants in terms of the product of research has been enforced through the legacy of objectivity referred to above. Stanley and Wise (1993: 115) explains that the product or interpretation produced by the researcher in terms of this legacy frequently purports to discover "the" truth – as though saying, "what is really going on here (though the participants but only dimly appreciate it) is this…". Stanley and Wise suggest that this occurs because "the researcher's account" and "the participants' account" are seen as competing attempts to get at "the" truth of the situation - that is, at the one true reality. As the evaluation of these competing accounts often rests solely with the researcher, "deviant" views of "reality" may be easily explained away by being treated as eminently refutable simply because those who hold such views – the participants – do not have the power to dispute the researcher's interpretations. The implications of this could be far-reaching because what the "powerful" researcher chooses to represent (perhaps despite the "deviant" views of participants) might explore only one possibility – thereby silencing other equally or even more important stories (Heaphy 1998: 34-35).

There is still a further important aspect of the research process which leaves participants particularly vulnerable: the researcher has limited control over the interpretation of research products. The researcher operates in complex and shifting political contexts – contexts in which he or she seldom has full control over the interpretation and use of the research products. This means that "the possibility is always before us that our carefully negotiated research relationships mutate from intimacy and equality" into the exploitation of those "who may be affected by the revelations which we make" (Small 1998: 136). Finch (in Lee 1993: 111) records for example her worry that the data she had collected from women on the basis of trust could, given a particular interpretation, be used against their interests. For Finch, the

dilemma here was not simply an ethical one, but ultimately involved a political choice of the "whose side are we on?" kind.

To re-align the rather unequal distribution of power within the research relationship, researchers have often reverted to what Barbour (1998: 189) calls "member validation techniques". These techniques, which involve participants in "validating" the product of the research process, appear to vary considerably in the extent to which participants indeed become involved and are able to exert any meaningful influence on the final product produced by the researcher.

A common attempt towards a realignment of the balance of power within the research relationship is that of giving a draft of a research report (or part thereof) to research participants and asking them to comment on its validity. This practice, Opie (1992: 62-63) explains, represents a direct attempt to avoid misrepresentation and to expand the researcher's appreciation of the particular phenomenon as a result of discussing and reworking the text with the participants. It also involves participants more directly by giving them a greater say in the final interpretation. It is however not clear how exactly this approach is to play out in the actual research context – and more importantly, how agreement over the final version is to be reached.

Acker et al's (1983: 428) research experience shows that an attempt to involve research participants in the production of the final product is not entirely straightforward. In an attempt to reduce the power differential between the researcher and the researched, Acker et al were initially willing to share and discuss their interpretation of the research data with all their participants. However, their intention to do so was restrained by a growing awareness of the possibility that their interpretation of participant's lives may, in some instances, be radically different from participants' own interpretations. Hence, while they did present most of their interpretations to those participants with whom they shared a particular world view, they only reluctantly offered material to those who they expected would experience the product not only as different, but possibly even as threatening and disruptive to their own view of the world.

The tension between the goal of producing a more equal research relationship and the difficulties of carrying this out when there is a lack of agreement on the meaning of experiences and the construction of realities, was echoed in this study:

> Towards the end of the first interview, participants were requested to complete the TSCS. Desiring not to leave them entirely empty-handed after their dedicated cooperation – and hoping that it would open further avenues of inquiry – I offered to share the interpretation of this instrument with them during the second interview. This was however far more difficult than I had anticipated. Far from working towards a less skewed relationship, this "validating technique" placed me in an awkwardly powerful position. I – the superior researcher – was presenting results to them – the "but dimly aware of their own circumstances" participants. This distressful situation was worsened in cases where the participants were likely to find the interpretation that I presented disturbing. In one case, I had to tell a participant (as tactfully as possible) that her scores revealed that she was unwilling to commit to any specific standpoints and that the picture of her self-concept gained through the TSCS questionnaire could consequently only be regarded as tentative. Transcripts of the interview clearly show how uncomfortable I was doing so. I hesitated, procrastinated, rephrased… and rephrased some more. The tension involved in sharing my interpretations with participants was exacerbated by the kinds of findings I needed to share. Worse yet, the very act of doing so appeared to entirely defy its true purpose: to establish more equal research relationships.

My experience substantiates Barbour's (1998: 190-191) contention that researchers should not underestimate the impact of exposing emergent (and often hard-won) embryonic insights to others who are unlikely to share their exact world view – let alone their disciplinary and theoretical concerns. And this impact touches both the participants and the researcher.

Requests to comment on analysis may represent something of an imposition on participants. Asking those who have taken part in our research interviews to listen to (or worse yet, read through) *our* construction of *their* reality makes considerable demands on time (and energy) – demands that might reinforce rather than abolish the power discrepancy in the research relationship. It also raises very important ethical issues. It is after all one thing to provide an account in a one-to-one setting, but another thing altogether to hear one's own reality

graphically included in another's version of that reality (Barbour 1998: 190-191). This was clearly a critical concern following my experiences described above.

Opening analysis to participants also makes it possible that, as Bloor (in Barbour 1998: 190) observes, "aspects of the research which the researcher feels to be of relatively little importance may be dragged centre-stage by the member, while the researcher's supposes central topic is disregarded". This suggests that, "when recruited to comment on our transcripts or emergent analysis, respondents may be equally selective and may react to inferences which exist only in the eye of the beholder – and an individual beholder at that" (Barbour 1998: 190). Participants may, in other words, disagree with our interpretation and may choose to focus on areas not even covered in our analyses. This again raises the issue of how exactly researchers and the researched are to reach agreement on contentious issues that may impact on the final interpretation. If researchers only pursue "validation" from participants in order to make their objections more "manageable", participants may very well have reason to mistrust our motives (Barbour 1998: 190-191).

Thus, although we aspire to the ideal of an equal partnership in the interpretation of research data, approaches such as those described above do not necessarily represent the best way of reaching it. These approaches appear to assume that participants will necessarily share our views, that they will unavoidably be interested in producing an account of the research data with us, and that this will somehow inevitably bring us closer to an equal distribution of power to the benefit of all involved. Yet this is clearly not the case. Participants might disagree with our interpretations, they might not be interested in meeting the demands of interpretation, and they might in fact (as my study shows) be harmed in the process of doing so. Approaches such as these, when uncritically applied, might indeed defy their very purpose. This of course does not suggest that we might as well deny the power we hold to "define" another's reality for them and for a wider audience. What it does mean is that while seeking to share this power with participants, no single approach can finally guarantee a fully equal distribution.

Conclusion

In sensitive research such as was undertaken in this study, the researcher recognises both implicitly and explicitly that he or she is actively involved in various sets of power relations and, to some extent, in research as a political endeavour. With this in mind, the ultimate ideal

becomes one of egalitarianism – of shared power and a greater awareness of power inequalities. As such, the stated ideal is very attractive. Research can now be conceptualised as a "political strategy" that aims to challenge the way expert or professional knowledge is privileged over local or personal knowledge. Yet, an awareness of power also brings to the fore contradictions and paradoxes.

When we recognise ourselves as powerful agents in the research process, we might choose to challenge this position on the basis of a common humanity we share with our participants. Yet, this might simply serve to disguise power inequalities under the guise of "sisterhood" and so leave such inequalities unchallenged. We might recognise the power participants are able to yield – yet at the same time acknowledge that they rarely do so because of the respect they have for the expert status of the researcher and the superiority of science in general. We might discover that we too are vulnerable, yet find ourselves silenced and effectively paralysed by the etiquette of the research interview itself. We might seek to promote more equal patterns of research through interactive research approaches, but discover that these are limited by notions of "objectivity" permeating the public arena. While we might like to establish an equal exchange of information, our participants might, under the impression that objectivity calls for silence, resist such attempts. Similarly, our attempts to involve participants in the production of a fair interpretation might be nullified by the erroneous assumption that they actually *want* to become more involved.

So we earnestly seek to locate – and re-locate – power within the research relationship, yet without the desired effect. We have recognised ourselves as part of a political endeavour, but seem unable to negotiate the conflicting interests and expectations to work towards a fairer distribution. Thus, the attempt to locate power when it confronts us in the research context becomes one of the most critical paradoxes – and tensions – in modern social research. It is a paradox that serves to transform the ideal of equal research relationships into something we strive towards and agonise over, but never seem fully capable of reaching.

The virtual inevitability of inequality of power within the research relationship, underlines the importance of presenting a construction of the relational context through which a particular understanding was developed. In this way, the influence of the researcher and the researched, and the paradoxes and tensions that mark their interaction, become open to scrutiny. In this way the political strategies that serve to empower – or conspire to disempower – become part of the understanding of research as an opportunity to dismantle the power relationship.

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Chapter 18

The practical implications of emotion

Lofland and Lofland (1995: 14) warn that an excess of self-reflexivity can lead reports to be viewed as "narcissistic and exhibitionist, and simply dismissed as uninteresting". In addition, like Burton (in Masters 1998: 80), I too believe that it is in reality impossible for researchers to be aware of all their assumptions and characteristics that may impact on the research. And perhaps like Johnson (in Masters 1998: 80), I too am sceptical of attempts by researchers to "let the reader know that they cried twice, made love fifteen times and changed their socks once a week while in the field". However, while heeding this advice, I agree with Masters (1998: 80) that it should be acknowledged that the researcher's own experiences will to some extent affect the priorities given to certain topics in the collection, interpretation and representation of the data. And a critical part of such experiences – and the focus of this chapter – is the researcher's emotions.

Traditionally, little attention has been paid to the place of emotions in research. Bourne (1998: 90) holds that "much scholastic work never discusses the emotional dimension or impact which the research has or had on researchers, and most methods chapters are bereft of discussion on this subject". Yet, recently, this has begun to change. A focus on "the researcher's self-reflexivity and the power of emotion in the research process has emerged" (Gillbert in Bourne 1998: 90).

In line with this shift, this chapter will place the academic taboo on emotion within the broader context of objectivity, present an argument against such a taboo, and explore the ways in which emotion did impact on the researcher and the research process in the study of the subjective illness experience of ME sufferers.

Emotion and the ideal of objectivity

In terms of traditional academic conventions, it is the participants' emotions which are regarded as "data" – not the researcher's. The researcher's emotions are rather regarded as "incidental" to the research enterprise at hand, as external (Bourne 1998: 92). The

construction of "emotion" as irrelevant to the research process is closely associated with the ideal of objectivity.

Acker et al. (1983: 427) observe that the methods directed towards the ideal of objectivity "are designed to separate the knower from the object of study". Where such a separation is achieved and maintained within the context of a particular study, such a study could claim to provide objective knowledge – as "the" truth – independent of the potential bias which accompanies the subjective (emotional) experience of the researcher (Mouton 1996: 24). It is then only the sufficiently detached researcher who would possess the necessary objectivity and emotional distance to conduct truly valid research.

This line of argument furthermore urges the researcher to resist the "pull toward ever greater inclusion and involvement" (Adler & Adler 1987: 15). This "pull" might stem from the research participants or even more strongly from within the researcher. Yet, the researcher must resist involvement for warnings against "going native" and "over-rapport" abound. At the extreme, involvement may lead the researcher to entirely abandon the task of analysis in favour of the joys of participation, or the researcher may identify with participants' perspectives to such an extent that it becomes impossible to see these as problematic (Adler & Adler 1987: 17; Hammersley & Atkinson 1995: 111). More subtle perhaps is the danger that "over-involvement" might in some way influence or change both the researcher and the researched. This would, it is held, almost inevitably introduce "bias". Such bias would clearly invalidate the scientific claims of the study, since it would be impossible to discern which information might be coloured by the researcher and researched's response to each other and which information is independent of such "contamination". As a result, the study will be dismissed as slanted and will not be taken seriously within the scientific community. Personal (emotional) involvement by the researcher thus becomes condemned as doubly bad: not only does it (apparently) point to some form of personal degeneracy (into bias); it also places into jeopardy the hard-won status of sociology as an (objective) science (Oakley 1981: 41).

To avoid such offensive consequences, researchers are encouraged to assume an "attitude of objectifying" (Mouton 1996: 24): the research participant is to be transformed into an "object of study" to so create (and maintain) a distinct (and emotionally neutral) distance between the participant and the researcher. Yet, the ideal distance that can be established between the subject (researcher) and the object (researched) is limited. The fact is that any "manipulation" of the objects of study – simply regarded as sources of data – "can only be achieved via a

certain amount of humane treatment (Oakley 1981: 33). In other words, if the research participants or the objects do not believe that they are being treated kindly and sympathetically by the researcher, they will not consent to be studied and will not provide the desired information. A balance must therefore be struck between "the warmth required to generate 'rapport' and the detachment necessary to see the interviewee as an object under surveillance" (Oakley 1981: 33).

Oakley (1981: 35) argues that, within the context of "objective" research, "rapport" does not refer to a "sympathetic and harmonious relationship" as the dictionary defines it. Instead, rapport refers to the "acceptance by the interviewee of the interviewer's research goals and the interviewee's active search to help the interviewer in providing the relevant information" necessary to realise these goals. By defining and implementing the concept of "rapport" as such, researchers actively and continually construct the research relationship in a way that what becomes "known" is clearly separated from the subjectivity (or emotion) of the researcher.

In practice, this construction of the research relationship requires the researcher to occupy a "marginal position" (Hammersley & Atkinson 1995: 112). In keeping to this role, the researcher must be simultaneously part of yet also distant from the research setting, neither remaining a stranger nor becoming a friend. Lingering in this way between "familiarity" and "strangeness", the researcher is to observe the essence of ongoing activity and obtain intimate details on participants' experiences, while inconspicuously fading into the background and not volunteering the same information in return (Adler & Adler 1987: 19).

Conventional textbooks provide researchers with numerous strategies to avoid having to contribute *anything* personal to the research context. Oakley (1981: 36) for instance notes that such texts clearly instruct the interviewer to inform interviewees that they are there to learn, not to pass judgement or deliver any comment on the situation. Researchers should laugh off requests for their opinion or say something like "I guess I haven't thought enough about it to give a good answer right now", or "well, right now, your opinions are more important than mine", or "if you really want to know, we can talk about it after the interview". Alternatively, the researcher can only respond with "oh, that's a hard one", and continue with the interview. By pretending in this way not to have any opinions or not to possess any information that the respondent might want, the researcher avoids the danger of introducing bias in any form

(including emotion) into the research setting. That is, the research setting – and the data it delivers – remains sufficiently "separated".

Thus, in the interest of objective (*read*: unemotional) science, researchers are encouraged to establish and maintain a distance sufficient enough to separate them from the objects of their study. Such an (enforced) separation is endorsed as a safeguard against the dangers of over-involvement and emotional distortion. Yet, given the need for rapport to ensure participants' cooperation, the ideal distance remains limited. As a result, researchers must carefully negotiate their position on the fringes of the research situation – moving close enough to secure the data, yet not slipping too close to contaminate it in the process.

Exposing the illusion of separation

According to Stanley and Wise (1993: 161; 1983: 194-195), feminism asserts that the researcher who is subjectively involved in the research process stands embedded within a definite social relationship with the research participants. Contrary to the view of the research relationship expressed above, it contends that "the knower and the known are of the same universe, they are not separable" (Du Bois 1983: 111).

In rejecting "the illusion" (Acker et al. 1983: 427) of a separation between the researcher and the research participants, feminism negates the possibility of any division according to which the researcher is posited as "an abstract being" and the research participants as "the other" who cannot reflect back on or affect the researcher. In other words, the researcher is no longer regarded as an agent of research who is exempt from influencing and being influenced by the research process and its participants. Similarly, the active nature of the research participants is not simply dismissed or its implications buried by "controlling for bias". Feminism indeed challenges research practices such as these by striving to openly acknowledge the thinking, deciding, reacting, interacting, and interpreting nature of both the researcher and the research participants' involvement within the research process (Stanley & Wise 1993: 114).

In accordance with the feminist perspective, the dynamic nature of the researcher's subjective involvement within the research context needs to be directly confronted. Laslett and Rapoport (1975: 970-971), caution that such an explicit recognition of the researcher's subjective response to the research situation and its participants is often accompanied by a tendency (as

we have seen above) to "throw the baby out with the bath water" by labelling the study, however systematic, as "impressionistic". Such a study is, in other words, regarded as seriously biased by the researcher's own experiences within the research context.

In contrast, Berg (1984: 226) claims that the researcher's subjective experience of the research process is not merely a source of bias or reactivity. Instead, it indicates the very context in which research takes place. In the light of this, Berg encourages researchers to examine more closely the nature and effects of their subjective and emotional responses to the research process and to the participants it involves. Such an examination is likely to support Snow, Benford and Anderson's (1986: 387) view of the researcher's direct experience and involvement as a critical source of information. Researchers are after all not simply recording instruments through which participants are able to make visible their personal experiences. Researchers – and their personal experiences – are integral to the research process (Edwards 1993: 184-185).

Collins (1986: S29-S30) confirms the importance of the researcher's personal biography as a significant source of knowledge. In contrast to approaches that require submerging this dimension of Self in the process of becoming supposedly unbiased, objective social scientists, Collins urges researchers to bring this way of knowing back into the research process. By doing so, researchers can employ – and benefit from – a powerful balance between the strengths of their scientific training and the offerings of their personal and emotional experiences. Neither is subordinate to the other. Instead, experienced reality is used as a valid source of knowledge for critiquing scientific facts and theories, while scientific thought offers new ways of seeing that experienced reality.

Against this background, it becomes possible to join other authors (Adler & Adler 1987: 84-86; Devault 1990: 102-104; Opie 1992: 59) in arguing in favour of researchers drawing more deliberately on their complex and multifaceted human Selves. Such a disciplined and sensitive employment of personal involvement and experience is believed to support the researcher in achieving the closest possible understanding of the social world being studied.

I agree with Wilkins (in Bourne 1998: 93) who says that the researcher's emotional response to the research experience "can foster a sophisticated sensibility in the research setting and enhance sociological understanding". Bourne (1998: 95-96) also specifically suggests that emotional responses may aid such "a sophisticated sensibility" in at least two important ways.

Firstly, "an awareness of our own feelings can have a 'sensitising, cognitive function which alerts us to the meanings and behaviours of others'". Secondly, our responses "have an important 'interpretive function', acting as 'a medium through which intuitive insight and inchoate knowledge arise'". In short, the researcher's emotional responses, once admitted into the realm of social research, can powerfully aid the development of insight and understanding.

There is still a further spin-off to openly recognising the importance of emotion in the research context. When considering the practical implications of the strategies mentioned above, researchers would have to respond to serious and important questions from participants by a head shaking gesture suggesting "that's a hard one" or simply laugh it off while remarking that their job is to get opinions, not to have them (Oakley 1981: 48). Far from supporting research, such responses quite reasonably may alienate participants from the researcher – and worse yet, to instil a sense of being exploited as a mere source of data. In contrast, when the researcher is allowed to admit his or her emotional experience into the research encounter, such personal involvement becomes an important condition for preventing research participants from feeling exploited or objectified (Maharaj 1997: 210).

Thus, instead of insisting on a perfect separation, it is clear that social research requires a recognition of the dynamic ways in which the researcher and the researched interact and influence one another. As part of such a recognition, it becomes possible to see the researcher's personal experience of the research process as an important way of knowing. This dimension no longer needs to be excluded at all costs or even considered as a limitation or a weakness. Rather, it should be incorporated as an integral part of the data available to the researcher. Once admitted in this way, the researcher's personal involvement (and emotional response specifically) becomes a powerful resource in the development of amicable research relationships and sensitive understanding.

Emotionally charged research

In response to the stories constructed by participants I experienced, like other researchers (cf. Bourne 1998: 91-92), a range of emotions during the course of the research process – laughter and tears, happiness and grief, love and anger, longing and fear. During the course of a single interview, the range of emotions expressed and experienced shifted and merged, some more

intense, others carefree. Sad memories loomed like black clouds overshadowing the research encounter. Happy memories recalled as treasured moments were brought back to life.

For many of the participants, especially where the research ventured into very sensitive areas, this experience was one where intensely personal feelings and private emotions found expression in the public arena of the research interview – often for the first time. Despite the deeply emotional state related during and experienced within the interview situation, the personal emotion of the researcher is typically expected to remain intact. That is, while eliciting emotionally intense accounts from participants, I was expected to keep my emotions firmly under control – almost as though I was untouched by the experience itself.

Yet, during the present study, a number of instances revealed the very real impact of the research experience on my Self. These occasions not only evoked responses such as confusion, anger and distress (which are not conventionally considered appropriate for the researcher to display in an interview setting), but more importantly, they also highlighted my own position and responses, my presence and my influence, within the study.

The occasion described below affirms the importance of critical reflection (cf. Chapter 7) where the researcher's experiences appear to be very similar to those of the researched. Such similarity creates the potential for close identification with participants – an awareness noted in this study as well as shared by Reay's (1996: 65) research experience. For Reay, the affirmation of finding her Self at the core of some of her participants' accounts contained "enormous power". In these accounts, she was able to read her own centrality "where so often there has only been partiality".

This experience is echoed in the deeply emotional sense of identification described below:

> After several conversations with Natalie as well as after working through her autobiographical sketch, I noted in my field diary that I had found great consolation in hearing about another's person's suffering, fears, uncertainties and experiences. More significantly, I had also found my self in Natalie's experiences. I had seen my self in her recollections. And I longed to say, "I know, I've been there, I understand exactly". I was utterly amazed by the degree of agreement and similarity between our experiences. We appeared to share so much. Yet, comforting as this experience might have been, I also suddenly found myself fully centre stage – and it was disconcerting. How should I respond to this emotional awareness of identification? Should I retreat into the wings? Or should I linger on centre stage and enjoy the view it makes possible?

The entries in my field diary tell of a struggle to place my Self amidst the very strong emotional experience of identification. I cherished each encounter with Natalie, yet each one brought uncertainty. On the one hand, I wished to linger in the experience of identification, counting on the unique insight it might offer. Yet, was such identification in any sense "real"? Could I really say, "I understand"? I after all knew well enough that something like empathy or fellow-feeling was not possible in the sense of reliving her experiences, least of all through my own. On the other hand, I had the option to retreat into the wings, reasoning that greater distance would bring greater perspective. How far to retreat was of course a different question.

The emotional experience of identification with the participant clearly introduced tremendous uncertainty. Yet, contrary to what might appear obvious, the solution to this dilemma eventually did not lie in finding the perfect position to place myself. Rather, like for Wilkins (in Bourne 1998: 96), the more productive approach appeared to lie in using the emotional experience itself. By analytically exploring this emotional response, I could work with and beyond it towards analytical insight. I could recognise (as Reay did) that being centre stage "is no less a position of limited vision than standing in the wings" (Reay 1996: 65). And what was critical (and far more interesting) was not the limitations but the unique analytical opportunities these positions made (make) possible.

When placing my Self – and my emotional responses – under the analytical spotlight, I became able to identify the "triggers" that provoked a strong emotional reaction on my side. What bored me to tears? What captured my attention instantly? The incident described below identifies a trigger that evinced in me one of the most prominent and vehement emotional reactions:

> Already at an early stage of the research process, I noted in my field diary that I tended to react very strongly to the injustice endured by ME sufferers simply because they had the misfortune of suffering from an illness very few people understand. By "injustice" I referred to the acts of doctors and others based on their own blatant ignorance – acts that hurt the ME sufferer emotionally, mentally and physically. I reacted very strongly to such acts, becoming deeply frustrated in the face of such ignorance and hurtful behaviour. This response was especially triggered during interviews when participants recounted one hurtful encounter after another. During one such an interview Cheryl recalled a "dreadful" Friday morning in hospital. She was desperately ill and in unbearable pain. Yet, despite this, the doctor simply accused her of suffering from "primadispomania" – which upon looking it up in the dictionary at home she discovered refers to "an uncontrollable urge for alcohol". He also emphasised that she must not expect any pain relief from him. When she responded that she only ever received strong relief in hospital and could therefore hardly become addicted to it, he looked her straight in the eye and said "you know where to buy it on the street, don't you". He finally left her bedside saying that if she did not see a psychiatrist immediately, she should find herself another doctor. Cheryl was stunned. Another ghastly experience in hospital. Again all hope of relief destroyed. I was horrified – and incredibly sad.

Such cruel injustice. I could not but respond emotionally.

My response reveals more than compassion and shared sadness. It also testifies to the presence of certain presuppositions on my side. My reaction does after all clearly suggest my belief that to behave in such a way towards a desperately ill patient is simply wrong. This judgement clearly shows that I am no blank slate, no tabula rasa. I am not a simple recording instrument that remains wholly unaffected by the research experience. On the contrary, I not only have certain qualities and characteristics that influence me, but I am also the owner of a

set of presuppositions, beliefs, and prejudices – in fact, an entire conceptual framework of personal meaning that is at work during every moment of research.

This assertion needs clarification. When I declare that I have a definite conceptual framework, all seems to be in order. Yet, when I admit that I hold certain prejudices, the reader might assume that this is unfortunate for, if not out-right detrimental to, the study. However, I do not necessarily believe this to be the case. I rather choose to follow the line of thought set out by Gadamer (in Maso 1995: 13-14). For Gadamer, "prejudice" does not coincide with unfair and unfavourable feelings or opinions not based on reason or enough knowledge, nor does it result from fear or distrust of ideas different from one's own. Gadamer sees "prejudice" more like something one would call a "pre-understanding", that is, "a judgement that is given before all the elements that determine a situation have been fully examined". When regarded as such, my prejudices – my pre-understandings – become the very conditions through which I experience something, through which I encounter an Other. Prejudices become, then, the pre-condition, the very basis, for all (my) human knowing and understanding.

At the very foundation of my way of knowing, I can never escape from my prejudices. I can never entirely bracket them. I can never simply hold them in abeyance. Nor do I really want to, for as long as I want to experience and understand the social (human) world, I cannot do without my prejudices. Their adamant presence and influence, however, does not mean that my prejudices are entirely closed to doubt or modification. Instead, it is far more likely that when I bring the experiences of an Other into the spotlight of research, I will also be required to bring my own prejudices into a state of indeterminacy. In this state, they may be questioned, adjusted, or fused with new insights (Thomas 1995: 112). Of course, I can only risk them as such, and thereby apply my prejudices to the benefit of my Self and the research I conduct, when I am openly aware of them. And for me such an awareness followed from the recognition and analytical exploration of my emotional experience within the research context.

As I responded to instances of injustice, so too I responded (often with similar intensity) to the severe physical suffering experienced by my participants. In the process, my research experience directly challenged the idea that emotion – and specifically the researcher's emotional experience – could somehow be "irrelevant". In many research encounters I could not but recognise my emotion as a significant rather than a trivial aspect of the research enterprise – and more directly of the research relationship. Consider the following revealing instance:

> In my field diary I recalled a conversation with Cheryl. She was dreadfully ill – and had been so for almost three long months. She had just spent a week in hospital with no relief, and was feeling even more wretched than before. Her body was showing signs of severe swelling. Her eyes were swollen almost shut, she found it difficult to breath (and to talk), and she could hardly hold a tablet between her fingers. Worse still, there was no medical help at hand. Listening to Cheryl, literally hearing her suffering, coming to grips with the magnitude of her desperate situation, I could not but offer to help. How could I not? I referred her to a doctor I knew who would at least listen to her, if nothing else. And still this seemed so feeble. Similarly so the vague offer, "If there is anything I can do…".

This account might very well be used as a prime example of "over-involvement" – when the researcher disregards conventions about distance and separation, and intervenes in the research process in a way that inevitably changes (biases) the understanding it might yield. Yet, I ask, could the emotional response which prompted such personal involvement not be integrated as part of the emerging understanding about the subjective illness experience associated with ME? My deeply emotional experience of compassion, I argue, should not be considered a source of bias, but rather as a rich vein which can provide important insights (cf. Bourne 1998: 96). It can point my investigation towards the theme of isolation in severe illness. It can lead me to investigate the lack of adequate medical care for the severely ill ME patient. In other words, my own experience (and involvement) becomes a springboard for asking more informed questions, for pursuing more relevant areas of inquiry, and for listening to my participants in new ways. In short, it becomes a way of knowing.

In addition, my emotional response (and the offers of help and assistance it evoked) was experienced as kind and considerate by the participant. Even if she decided not to take up the

offer, my response still conveyed the clear message that I did not consider her as a mere source of data, as the "object" of my study. In contrast, an emotionally neutral response such as "Oh, that's a hard one" would certainly have served to alienate the participant. It would have trivialised her experience. And it might very well have marred the research relationship. By this I do not suggest that researchers should become excessively involved in the research context. Neither do I maintain that researchers should proceed to intervene without hesitation. In fact, researchers should never be encouraged uncritically to carry out any acts, however good-intentioned or seemingly harmless. Experiences by numerous researchers attest to this (e.g. Bloom 1997: 112-116; Acker et al. 1983: 428). Yet, what is clear is that an awareness of emotion guards against inhumane and insensitive strategies and approaches. In this way, emotion contributes not only on a methodological level, but also operates and supports the researcher at a more normative-ethical level.

By inviting participants to share their stories, I was asking them to give expression to emotionally intense experiences. These stories elicited an emotional response – a response I believe allowed for the collection of richer data and the production of more subtle analyses. In this, I affirm Wilkins' (in Bourne 1998: 96) view that, when combined with analytical rigour, the researcher's emotional response to the research experience can foster "a sophisticated sensibility" in terms of both the research relationship and the development of sociological insight. Thus, instead of being regarded as a mere weakness that should be ignored, I viewed emotion as a powerful resource in this study.

Emotion and responsibility

The conclusion reached above strongly encourages researchers to examine more closely the nature and effects of their subjective (emotional) responses to the research process and the participants it involves. Such an examination is, according to Peshkin (1988: 20), likely to attune the researcher "to where Self and subject are intertwined". And as the researcher and the research participants are indeed inseparably "intertwined", an examination of the researcher's experience of the research should, as Laslett and Rapoport (1975: 970) recommend, be accompanied by a similar investigation into the active and reactive nature of the research participants' involvement in the research.

Laslett and Rapoport's position appears particularly applicable in sensitive research where powerful and emotionally charged responses are elicited from participants. The researcher has a critical responsibility in terms of the impact of such research on the participants (Bourne 1998: 96). Comments from some of the participants in my study on how drained and exhausted they felt – both physically and emotionally – after our interviews not only concerned me, but also impressed upon me the enormity of the responsibility I had undertaken in asking people to discuss issues of such intense sensitivity with me.

In an attempt to give due attention to the researcher's responsibility, I subsequently consider and place into perspective the main risks and benefits associated with participation in sensitive research, with specific reference to the participant's emotional experience of such participation.

Research is a "social act" that involves far more than the exchange of data. It can indeed be experienced as "therapeutic or cathartic" (Bourne 1998: 185). That is, during a research encounter, there is the possibility that participants will view the interview which gives them the opportunity to voice their concerns and share their experiences as a therapeutic session (Small 1998: 134). Participants might describe the study itself as positive in terms of allowing them to talk to an interested listener about their experiences – at length, without censure or criticism. This in turn gives them the opportunity to validate their life, to discover its significance, and to develop a fuller understanding of their situation (McBeth in Bourne 1998: 185).

In this study Cheryl expressed an awareness of the therapeutic qualities of the research process:

... it has not been anything other than cathartic to have someone prepared to listen to you... I mean, I can force friends to sit down and listen to me... but you actually *wanted* to. That's good... that's excellent, be it emotional, physical, whatever... it's *very* good to have somebody who wants to listen to you... So, I think, generally... that's the best thing... is to have had a chance to talk *endlessly* on this *incredibly* boring subject, boring to everyone *but* the sufferers...

For Cheryl and the other participants in the study, taking part in the research gave them space – or even ceremonial permission – to talk about and make sense of their "reality". Using Parkes' phrase, Bourne (1998: 97) strikingly describes this experience as the "quiet catharsis of comprehension". Unfortunately, it is not clear how long such research induced insights last, or how easily they are translated into change for the participant.

While sharing one's experiences and concerns may in itself be therapeutic, serendipitous positive outcomes are not necessarily assured within the context of sensitive research. Small (1998: 134) points out that interviewing people about sensitive topics may expose emotional problems whose interpretation and handling may ideally require the interviewer to possess therapeutic skills. Thus, the interview inadvertently becomes something that neither party felt they were contracted for and neither may be ready or able to pursue satisfactorily.

This possibility – of exposing emotional trauma without being equipped to deal with it – suggests that it is imperative that the research interview is differentiated from a counselling session. Stark (1998: 206) explains that counselling suggests a relationship to which parties bring certain expectations and where they enter into a type of "contract" to ensure that these expectations will be realised. However, an interview seeks out information, and an interview for the purposes of research does not have the overt goal of helping the participant. If some good does come out of a research encounter then this is an added bonus, but still purely secondary to the interview's primary purpose. Thus, the role of an interview itself is to gather information in order to develop a better understanding of the phenomenon of interest. It is not to help, change or council.

While the distinction between counselling and research are described here as complete opposites, in practice it is not always easy to maintain this separation. Where boundaries become unclear, the researcher's best intentions might not be sufficient to ward off all possible adverse outcomes. "In our efforts as social scientists to gain insight into the world of others", Bourne (1998: 97) explains, "we sometimes forget that no matter how skilful and careful we are – or believe we have been – we sometimes can (and do) inadvertently cause distress to the respondents themselves". This is a possibility we cannot escape, especially not within the context of sensitive research.

Given the potential for unforeseen – and unwanted – outcomes within the research encounter, careful management and critical reflection to ensure sufficient sensitivity to the needs and expectations of all parties become imperative. Laslett and Rapoport (1975: 970) support this view, maintaining that the research encounter can only benefit from a stronger awareness and more deliberate management of the nature and implications of participants' involvement in a research study. This is exactly where the researcher's responsibility becomes most critical…

The management of research participants' responses to the research and the research situation may, according to Laslett & Rapoport (1975: 970), be facilitated by a direct attempt to work with participants through their personal and emotional experience of the research process. This practice is exemplified in Cannon's (1989: 67-69) study of women suffering from breast cancer. Cannon strongly encouraged her participants to regularly discuss their personal and emotional experience of the research encounters. This practice evolved differently with individual women. With some, lengthy discussions occurred on almost every occasion. With others it was simply a case of their saying if they thought the encounter had "gone well", or if any part had been difficult for them. As a result of these discussions, Cannon came to view the research encounters as a collaborative effort that offered critical insight into the interpersonal dynamics of the research process.

In following Laslett and Rapoport's advice and learning from Cannon's experience, I deliberately endeavoured to not only remain sensitive to participants' responses, but also to make them aware of the opportunity to collaboratively shape the research encounter. And as in Cannon's study, this approach evolved differently for each participant. In some cases, I became attuned to participants' reactions to those aspects most likely to cause them distress. In response, I left the broaching of such subjects largely to the specific participants. Throughout, I needed participants to know without a shred of doubt that the opportunities to direct the extent of openness in our dialogue was also in *their* hands.

In other cases, participants chose to share their experiences of the research process only after the last interview, which was not entirely ideal. On one such occasion Natalie described her experience of the research relationship:

Dis 'n *baie* moeilike proses vir my om... *soveel* van myself vir jou te gee en te sê... soveel diepte... dinge... daar's dinge wat ek vir jou nou moes sê wat ek... byvoorbeeld oor my... jy weet... dis nie iets wat ek met enige iet... enige iemand wil bespreek nie, dis *baie* persoonlik... mmm... daar's omtrent nie iemand wat daarvan weet nie. So, ek het nou aan jou goed verduidelik en gesê en tog het ek *niks* van jou geweet nie en *niks* van jou gehoor nie. En... mmm... daar bly die heeltyd 'n gevoel by my dat... ek *weet* jy's ook siek en ek *weet* dat jy ook probleme het en ek wou so graag iets terug gekry het, iets van *jou* gehoor het... Nou, ek het besef... ek het daaroor gedink... en ek het besef... jy's besig om nou hierdie studie te doen en jy kan my onder *geen* omstandighede lei in 'n rigting nie, *jy mag nie*. So, jy mag nie eintlik vir my enigsins iets sê van jouself nie, maar dit was vir my *baie* moeilik...

While she is apparently a "properly socialised" participant who politely refrains from asking questions back (cf. Oakley 1981: 36), this "unnatural" situation introduced a considerable degree of strain for Natalie. For the point is exactly that the research interview is an unnatural

situation. One very rarely finds oneself in a situation where so much is expected to be said by one party, while virtually nothing (or then at least nothing of great significance) is divulged by the other. In this sense, Natalie's comment is especially insightful as it highlights the potential for strain and distress – however unintentional – and thereby the need to manage participants' experiences even more directly than was the case in this study.

Emotions in the writing

Analysis and writing up, as Bourne (1998: 99) puts it, "tend to be time-consuming and somewhat lonely pursuits", even where the topic involved is less emotive than the one under discussion here. My own reluctance to embark on this process was however related to far more than the demanding nature of the task that lay ahead.

To analyse the data I had gathered I needed to reread transcripts from the interviews. When doing so, the emotional charge in them literally leapt of the page. At times, it felt as though suffering was everywhere, on almost every page, in all the stories, in so many paragraphs. The data appeared almost consumed by the emotions it carries. Occasionally I also had to listen again to the recordings made during the interviews. This led to an even more detailed recall of the different interview settings. I heard the tones of voice and the significant silences. I remembered the body language. And I remembered the tears.

Time and again, revisiting the data in this way brought the interview back to life for me – and with it the emotions encountered in it, be it positive or negative. For me, the emotional experience evoked during this process of recall and analysis was incredibly (and perhaps surprisingly) intense.

To deal with this effectively, I found it imperative to externalise my emotions in some way. And, much like Bourne (1998: 99), I turned to my field diary. In this field diary, as I explained in Chapter 8, I attempted to disclose my Self as a significant source of both insight and knowing. I explicated the reasoning behind the procedures I employed. I reflected upon the multitude of encounters I had experienced. I noted and examined my own assumptions, beliefs and presuppositions in terms of their effect upon the research process. And I detailed my emotional responses as part of my very personal experience of this research enterprise. The notes recorded in this format – specifically in terms of my personal responses – served as a

form of therapeutic writing as I attempted to come to grips with the emotions emanating from both the research encounter and my own personal biography. However, even after having done this, I was left with very little guidance from the literature with respect to ways of integrating such emotional "off-loading" into my emergent theoretical analysis.

This awareness of limited professional guidance and support in dealing with the emotional impact of the research process is echoed in Bourne's (1998: 99) research experience. Bourne refers to the concept of "emotional exile" to describe her experience – or rather lack of experience – of emotional support during the research process. She argues that it is the lone researcher – and then specifically the research student – who may be most vulnerable to such "emotional exile". This, Bourne (1998: 99) speculates, "may be partly because of their reluctance to admit to significant others that they are becoming emotionally embroiled and drained by the research they are undertaking". The profession after all strongly discourages a discussion of the emotional aspects connected to (let alone impacting upon) a research project in the public area. More importantly, "as trainee researchers, we are taught and encouraged to perceive our research as 'data'". And "data are often portrayed in the abstract, to be interpreted and analysed, with no room for emotional entanglement" (Bourne 1998: 99). The researcher, in other words, is expected to keep a controlled state – not only in the research setting, but also when doing the analysis and when interacting with professional others. Only then (it seems) will the work conducted be recognised as undertaken with visible competence and will it enjoy credence in the scientific community.

Given this perception, it is hardly surprising that I found little direct guidance in dealing with the personal and emotional responses evoked by and experienced within the research process. This, however, does not appear to be the case in other professions. Prior to initiating the fieldwork phase of this study, I enjoyed a brief conversation with a researcher who had been engaged in similarly sensitive research. She explained how emotionally draining she had found her encounters with participants, and that she had used the services of a counsellor to off-load. This researcher was active in the field of psychology – a field in which the need for "debriefing" is well recognised and the practice of mentorship for younger researchers well established. Unfortunately, this is not the case in sociology – not even where intensely sensitive research is undertaken. The researcher suggested that I might wish to consider making similar arrangements for "off-loading" some of the more distressing aspects of my research. Looking back, I wish I had heeded her advice more closely.

For me, this experience points to the need for a forum of some kind where at least the most disturbing aspects of sensitive research can be raised. Such a forum can assume the form of a counselling-like, one-to-one relationship, or even a "support group" for researchers engaged in sensitive or potentially emotionally draining research. Bourne (1998: 100) substantiates this by making the important point that such support can be very productively combined with analysis. In other words, a forum for support need not exist separately from the process of analysis. Rather, a combination of support and analysis can extend the latter in important ways and lead to a highly sophisticated understanding of the social world under study.

However, Bourne (1998: 100) cautions researchers against going too far, against using "support" to merely "intellectualise" – and thereby justify – emotions as part of the research process. This would after all only testify to (or worse, exacerbate) the academic community's discomfort with the notions of emotion and support as integral to scientific research. Instead, any recognition of emotion in research – be it individually or in the company of fellow scientists – should reassure and empower researchers to confront the academic taboo on the topic of emotion.

Conclusion

The school of objectivity, with its emphasis on distance and neutrality and its warnings against over-involvement and emotional distortion, requires researchers to tread a very fine line of keeping an interpretive distance from those under study, while simultaneously remaining close enough to understand experiences from their perspective. The practical and conceptual limitations of the obligation to remain emotionally detached – virtually at all costs – is thrown into particularly sharp focus by research involving people in severely distressing situations.

My study directly challenged the notion of objectivity and the concurrent embargo on emotional involvement. It became clear that objectivity does not necessarily represent the ideal – let alone the only – approach to scientific research. The position offered by objectivity, although once carrying great authority, is arguably neither more nor less valid than the position taken by a social researcher who is more engaged but equally perceptive. This recognition makes it possible to openly acknowledge and incorporate our own emotional experiences into the research process.

Indeed, we cannot – and should not – separate our sociology from our own emotions. An awareness of our own emotions should never be far away, because emotions are critical ingredients in the construction of a social reality. Any denial of them would only serve to blunt our sensitivity to their input throughout the research process. On the other hand, to be simply overwhelmed by our emotional experience is also not an option. This would leave us similarly stumped. Hence, to recognise and deal with emotions we need to create a (analytical) space where we can consider the full implications *and* potential of our emotional reactions.

Once given the space to do so, our own experiences can become a powerful resource in our academic endeavour. They can help us to enhance our perceptiveness and analytical engagement. They can help us to capture the true subtlety of the social reality under study. They can help us to produce work which is visibly connected to lived experience – our own and others'.

Thus, like Kleinman and Copp (in Bourne 1998: 91), I conclude: "We can learn a good deal more from the field by treating our feelings as aids to analysis rather than hindrances".

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Chapter 19
Research ethics in practice

When Sartre's student came to him for help in resolving a difficult moral dilemma, Sartre had but one reply: "you are free, therefore choose – that is to say, invent. No rule of general morality can show you what you ought to do: no signs are vouchsafed in this world" (in Cunningham 1970: 8).

Since Sartre's time, much effort has gone into the development of such "rules of general morality" or "moral principles"' to help us guide our actions in the face of moral dilemmas. The great number of ethical guides, codes, and definitions bear testimony to these efforts. There indeed appears to be as many definitions of ethics as there are users of ethics. One such definition that merits attention is that of the philosopher Louis P. Pojman (in Tong 1993: 13):

'"Ethics' (or 'moral philosophy,' as it is sometimes called) will be used to designate the systematic endeavor to understand moral concepts and justify moral principles and theories. It undertakes to analyze such concepts as 'right,' 'wrong,' 'permissible,' 'ought,' 'good,' and 'evil' in their moral contexts. Ethics seeks to establish principles of right behavior that may serve as action guides for individuals and groups. It investigates which values and virtues are paramount to the worthwhile life or to society".

Thus, as Pojman's definition suggests, ethicists have traditionally been concerned with the development of ethical systems that aim to discover, articulate, and interpret the ultimate moral principles that should guide our actions.

In accord with this definition, an ethical system in the domain of research should then be able to guide (or even "govern") our research actions. That is, it should be able to help us (perhaps more than Sartre helped his student) in making morally difficult choices within the research context. During my study I repeatedly confronted problematic incidents which eluded an easy solution through the application of "ultimate" moral principles of right behaviour. These incidents specifically demanded critical reflection in order to arrive at a better understanding of the relevance of ethics in a critical research interview situation where the participant's precarious state of health imperils the actual progress of the interview.

While a number of different approaches were considered, I limit the present discussion to those four approaches that influenced my reflection most directly. The first two of these ethical approaches – utilitarianism and deontology – have literally dominated the moral landscape for centuries through their emphasis on general laws or values that guide moral decision-making. In response to their dominance, alternative schools of ethical thought have developed. In particular, I consider situation ethics and relational ethics that demand that the unique situation, as well as the individuals involved in it, should be taken into account in the face of any given moral dilemma.

I will now explore the four ethical approaches, at first in the abstract, and then as they in practice influenced my actions in the research context. The chapter will conclude by calling attention to some of the most important implications of my research experience and to how these, at least for me, point the way towards an alternative practice of ethics in social research in general, and in sensitive research in particular.

Utilitarian ethics

Utilitarian ethics is based on the principle of "utility" or, as first described by Mill (1991: 137), "the Greatest Happiness Principle". It can be defined as "the doctrine that the rightness and wrongness of actions is determined by the goodness and badness of their consequences for all concerned" (Cunningham 1970: 36). In general, this means that when deciding what would be the moral thing to do, a utilitarian would insist that one should choose that action which promises to produce the maximum of good for all concerned. The directive to make decisions based on their consequences is supported by our ordinary expectation that all moral agents will (and should) take the consequences of their actions into consideration when deciding how they should act. Within the research context, utilitarian ethics require that the researcher should weigh the consequences of each alternative action in terms of its desirability (that is, its capacity to produce "happiness") and then select that action which will do the maximum good (Kolnai 1970: 247; Mill 1991: 137).

However, this approach assumes that the moral agent is "properly equipped with intellectual power, relevant information, and experience concerning various similar models of practice, enabling him to perform such a calculus of foreseeable consequences pertinently, with a high degree of objective probability" (Kolnai 1970: 247). We can reasonably assume that to

competent apply such a practice of extensively calculating all foreseeable consequences of a single research encounter (let alone an entire study) lies beyond the reach of many an otherwise proficient researcher. What is more, what if the researcher is confronted by a choice between two equally appealing alternatives through which to produce "happiness"? How should she decide which course to follow? In such an event, Mill (1991: 139) advises the moral agent that "if there be one to which all or almost all who have experience of both give a decided preference, irrespective of any feeling of moral obligation to prefer it, that is the more desirable pleasure". Yet, is it not unreasonable (if not wholly impracticable) to expect the researcher to first embark upon a sophisticated analysis of the impressions of "all or almost all who have experience of both" before making a decision in the immediate research situation?

Furthermore, the utilitarian emphasis on "the greatest good for the greatest number" reveals an apparent willingness to sacrifice the rights of one or a few individuals (such as the participants in my study) in order to secure the greatest good of many other individuals (say, of society as a whole). In this, utilitarianism clearly assumes that people will always be induced to promote the general interest of the greatest number. This assumption, says Tong (1993: 15), weakens the moral credibility of utilitarian ethics, because most people – including many researchers – do not believe that morality requires extreme levels of (self-)sacrifice. Consequently, utilitarianism may be perceived, perhaps rightfully so, as too demanding (Tong 1993: 15-6).

A last criticism that may be levelled against the utilitarian approach concerns its emphasis on impartiality. Mill (1991: 148) clearly states that when it comes to a choice between the "happiness" of the moral agent and the "happiness" of others, utilitarianism requires the moral agent "to be as strictly impartial as a disinterested and benevolent spectator". According to Mill's moral reasoning, all persons must be treated as persons. Consequently, when it comes to responding to the needs of another person, "his/her relationship to me is irrelevant. It does not matter whether s/he is my best friend or my worst enemy" (Tong 1993: 68). Such "moral impartiality" clearly requires us to detach ourselves from the other (in fact, from all others). Yet, such detachment is neither feasible nor desirable. For in requiring researchers to manifest attitudes "such as detachment from personal concerns and loyalties, disinterest, dispassion, and a regard for the generalized moral equality of all persons" (Friedman in Tong 1993: 68), utilitarian-based impartiality may force researchers to jeopardise those very relationships upon which research rests. These are relationships that demand attachment, that demand something qualitatively different from the general "goodness" directed toward strangers (Tong 1993: 68).

Utilitarians (and other moral impartialists) may respond to this objection by arguing that to be solely concerned with the interests of those who immediately surround us as opposed to those of our region, nation and the world, is to be (or become) "parochial" (Tong 1993: 69). Hence, they would insist that the proximity of relationships carries "no moral weight and that moral responsibilities extend equally to all members of the global village" (Friedman in Tong 1993: 69). There is clearly some truth in this argument: "Our desire to attend to the needs of our loved ones should not become an excuse for the kind of moral laziness that impedes our ability to expand our conception of Selves to include more persons than those who immediately surrounds us" (Tong 1993: 69). Still, as Tong (1993: 69) continues, the researcher must confess that her "moral energy is limited". That is, while it is important for her to work against tendencies to be parochial, the researcher cannot expand herself into infinity. She will collapse. So, unless morality permits researchers "to be somewhat partial", and to so take full account of our relationships with our participants, "we will go stark raving mad" (Tong 1993: 70).

Thus, utilitarianism insists that the researcher as a moral agent should choose that action which promises to produce the greatest good for the greatest number. While this approach may almost inevitably be consonant with the interests of society (as "the greatest number"), it is clearly not unproblematic. It is plagued in particular by problems concerning the evaluation of "good". Here, utilitarianism appears to expect too much of the moral agent in terms of intellectual capacities as well as in terms of a willingness to sacrifice both the individual and individual relationships.

Deontology

Unlike utilitarianism, deontology is, according to Tong (1993: 19), "a nonconsequentialist ethical theory. Whereas utilitarians insist that an action's moral worth depends on its utility-maximizing consequences, deontologists maintain that it depends on some feature inherent in the action itself". In fact, in the deontologist's world, "it does not matter how much or how little utility (good, pleasure, or happiness) one produces as the result of one's actions. Instead, what matters is whether one's actions are motivated by the intent to do one's duty because it is one's duty" (Tong 1993: 19).

This is not to say that deontology discards the "good" that is so important to utilitarians. "Good" remains something that one should promote, but for the deontologist "goodness" is contingent upon the "moral rightness" of the action in question. The "moral rightness" depends in turn, as Warren (1997: 96-7) explains, entirely upon "the good will of the agent". And to have a "good will" is 'to be motivated to do one's moral duty and to do it simply because it is one's duty'. While this does not mean that in order to act from a "good will" one must suppress all kind and benevolent feelings, the deontologist insists that "such emotions must not be what directs the will towards the performance of duty" (Warren 1997: 96-7). Thus, an act can *only* be morally worthy when one performs it simply because one knows it is required, because it is one's duty to do so.

As "doing one's duty because it is one's duty" is so important to deontologists, they have taken great care to establish the most fundamental moral principles through which to guide action in any given situation. To this end, Kant has made the most notable contribution by proposing a single universal principle – the "Categorical Imperative" – from which all other moral principles may be derived (cf. Warren 1997: 97-8). According to Warren (1997: 98), Kant offered several formulations of the Categorical Imperative. Of these, the most pertinent to the present discussion is known as the "Formula of the End in Itself". In Kant's (in Warren 1997: 98) words, "man, and in general every rational being, *exists* as an end in himself, *not merely as a means* for arbitrary use by this or that will. He must in all his actions, whether they are directed to himself or to other rational beings, always be viewed *at the same time as an end"*. To treat persons as ends in themselves is to treat them as having "dignity" or "intrinsic value". This is a value "which is exalted above all price and so admits no equivalent". Thus, because persons are ends in themselves, their autonomy must be respected, not just as one component of utility, but as something that imposes strict constraints upon the ways in which they may be treated by others.

In view of Warren's (1997: 98) discussion it is important to note that Kant's "Formula of the End in Itself" principle does not condemn those who treat persons as means to ends that they have accepted. We do this in all co-operative human activities – including social research. It is, however, *not* permissible (it is even plainly wrong) to treat persons as if they were *mere* means, as things that we are entitled to use towards ends that are not their own. This condition would appear to place a limit on the extent to which a researcher (as a moral agent) can manipulate participants for the purpose of research alone.

Deontology is, however, vulnerable to several lines of attack; the first of which may be launched against its tendency towards abstraction. It asks of us, Tong (1993: 63-4) observes, "to submit all of our moral experiences to a single, overreaching behavioral index such as the categorical imperative". Consequently, it may be easier for the researcher to resolve never to cause detriment – not even for a good reason – than to focus on the exact ways in which certain individuals may be either harmed or benefited as a result of causing (or refraining from causing) detriment in a particular instance. When applied in this manner, the otherwise estimable moral rule "to respect and therefore not to cause detriment" turns into a "moral convenience" (Tong 1993: 64). For when armed with a categorical imperative, the researcher is apparently under no obligation to consider difficult questions. The researcher may simply – automatically and unquestioningly – apply the categorical imperative as a prescription for action (cf. Glen 2000: 21). Yet, a prescription that so directly eliminates the need for reflection must produce a "morally lazy" (Tong 1993: 65) researcher.

A deontological researcher is, furthermore, likely to confront differentials of power and *not* know what to do with it. Baier (in Tong 1993: 97) feels that the reason for this is that traditional ethical approaches – including deontology – have been primarily concerned with the regulation of relations "between equals or those who are deemed equal in some important sense". Relations between "those who are clearly unequal in power", such as parents and children, states and citizens, doctors and patients, the well and the ill, "have had to be shunted to the bottom of the agenda, and then dealt with by some sort of 'promotion' of the weaker so that an appearance of virtual equality is achieved". This represents a rather problematic approach within the research context (let alone outside it). The researcher cannot simply assume that all participants occupy a position of strength similar to his or her own. In fact, it is more often the case that the researcher (regardless of whatever efforts are made to the contrary) remains in a position of power throughout the research process. After all, it is the researcher who usually determines the agenda of topics to be discussed as well as the course and progress of the interview. There is indeed nothing abstract about the practice of research; "it must grapple with the way in which power operates... in a concrete and particular way" (Hekman in Usher 2000: 31). The "operation" of power within the research context cannot be ignored. For Baier (in Tong 1993: 97), any ethical approach which attempts to do so – which endeavours to discard or to downplay the differences of power between moral agents – amounts to a form of deception, even of self-deception. Unfortunately, as a result of such a case of "deception", deontology appears incapable of offering any sufficient help in the face of a moral dilemma caused by very real discrepancies of power.

The last criticism against deontology concerns emotions: Kantian deontology claims that "our feelings neither add to nor subtract from the moral worth of our actions" (Tong 1993: 22). For Tong (1993: 22), it is this point, more than any other, that weakens the credibility of deontology. "Doing the right thing", Tong (1993: 22) says, "counts for a lot but not as much as doing the right thing with the right feelings". Indeed, "a sense of duty devoid of emotion may be worse than no sense of duty at all" (Tong 1993: 23). Thus, while duty is important, it tells only a chapter of the moral story, the bulk of which is, in Blum's (in Tong 1993: 68) words, about "being responsive to the weal and woe of others". To be sure, this persuasion that the emotions underlying a particular action may contribute (either positively or negatively) to the moral worth of the action does not imply that duty should be ignored. But it does mean that duty or obligation should not necessarily take precedence over concern for the person before us. Perhaps it need not even be a case of *either* duty *or* concern, but rather of a desire or will to follow sound moral principles *in combination with* empathetic concern for others. Such a more encompassing approach may very well provide a particularly strong moral basis for the solution of many a moral dilemma (cf. Warren 1997: 143 & 158).

Thus, to adopt a deontological approach to ethical decision-making means to know what is right or wrong by the application of the categorical imperative and then to act accordingly because it is one's duty to do so. As important as the imperative is to respect the moral rights of the other person, it cannot be applied unreflectively. Such a mechanistic approach is likely to blind the moral agent to other important dimensions of a moral dilemma, including the possibility of truly conflicting courses of action, the presence of power differentials, and the salience of human emotion in human interaction. Far from being peripheral, these dimensions, together with mutual respect, are very much part of the solution to pertinent moral dilemmas within the research context.

Situation ethics

Fletcher (1970a: 56) says that there are essentially three lines of approach to ethical decision-making. One of them, perhaps the least followed, is the antinomian or non-principled (or even law-less) approach. Antinomians operate without the help of any moral principles. Instead, they spontaneously make their moral decisions wholly within the situation. The resultant unpredictability of such decisions stems from the fact that they believe that one "moment" of existence is so entirely discontinuous from others that we cannot generalise about our decision-

making. At the opposite end of the spectrum is legalism. Fletcher (1970a: 56) explains that this ethical strategy does take into account the "situational variables", but maintains that the circumstances are always subordinate to predetermined general "laws" of morality. In this sense, "legalistic ethics treats many of its rules idolatrously by making them into absolutes". Correspondingly, "obedience to prefabricated 'rules of conduct' is more important than freedom to make responsible decisions" (Fletcher 1970a: 56). Somewhere in the middle of these two extreme positions lies situation ethics.

According to Fletcher (1970a: 58), moral agents do not have to be either antinomians who make decisions without any principles at all, or legalists who absolutise ethical principles. Instead, moral agents can choose to be situationists who (like the legalists) acknowledge the heritage of civil principles of right and wrong, but who (like the antinomians) remain free to decide in all situations which principles are to be followed, or rejected, in order to secure more good than evil.

What is "good" for the situationist? For Fletcher (1970a: 58) there is only one intrinsic good: "the good of *people*". Fletcher calls this good "love" or "agapé" which, for him, denotes "a personalist devotion to people, not to things or abstractions such as 'laws' or general principles. Personal interests come first, before the natural or scriptural or theoretical or general or logical or anything else". For the situationist, then, the "moral goodness" of an act does not lie in its adherence to any general moral principle. This does not mean that situationism rejects all moral principles (Simons & Usher 2000: 2-3). Instead, it means that when it comes down to doing the "most loving thing", the situationist researcher is "prepared to bypass the rule" (Fletcher 1970b: 279). In fact, what matters more than any specific rule is whether the researcher's chosen action helps or hurts people; that is, whether it serves the purposes of agapéic love and so reveals a personal concern for the other person, the participant, in this situation (Fletcher 1970a: 59). Thus, what determines the "moral goodness" of an action, far from any strict adherence to a set of general principles, is the intent with which it is done and the consequences that it is likely to produce (Fletcher 1970b: 278).

It is exactly this conception of "moral goodness" that weakens the credibility of situation ethics. Situationists evidently sees that "moral goodness" follows from the practice of "agapéic love" – that demand to which all other moral obligations are subordinate and of which they are mere applications, proper to some situations but unsuited to others (cf. Kolnai 1970: 93). This conception clearly devalues the importance of general moral standards. But

does it go too far? Dupré (1970: 93) and Kolnai (1970: 233) feel that it does. These authors argue that in their attempts to emphasise the implications of *this* situation, situationists indeed become short-sighted. They can no longer see the more general, the abstract. They become unable to properly consider those universal moral standards that actually may have bearing on that situation. This "reckless lack of regard" (Kolnai 1970: 239) for general moral principles leaves the situationist vulnerable to many problems.

These problems stem from the fact that, besides lacking appreciation of the potential importance of general moral principles, the moral agent must seek and find moral guidance somewhere else. It would appear that "somewhere else" could only be one of two places: in the situation itself or in the demand for "agapéic love".

Dupré (1970: 93) maintains that to assume that a situation alone could offer worthy moral guidance would leave the moral agent with little but the meagre option to either face "perplexed inactivity" or engage in "self-deceiving rationalisations" of his or her "emotional inclinations". Such a potential welter of muddled reactions stems from the simple fact that "from the situation as such, from it alone, absolutely nothing – no moral imperative or direction, nor even a practical incentive or counsel – follows" (Kolnai 1970: 239). Situations do not – cannot – mysteriously "produce" moral motives to act (or to refrain from acting). Thus, the researcher cannot from the situation alone deduce what to do. Hence, while granting that the circumstances of a particular situation may influence the rightness or wrongness of an action, the researcher cannot presume that the situation alone is capable of providing the necessary standards through which to choose a morally worthy course of action (cf. Dupré 1970: 93; Kolnai 1970: 266). It would in fact be entirely misguided to hold a situation responsible for producing some course of moral action for the researcher to simply follow. Rather, to act morally requires a moral guideline. Such a moral guideline could then be applied with reference to the situation in question. Indeed, a moral guideline would have no meaning except by reference to an actual or at least a conceivable situation. Thus, contrary to an exclusive reliance on the situation for moral guidance, what appears more reasonable is an attitude that equally does justice to the concrete situation and to the abstract moral principles which apply to it (cf. Dupré 1970: 94).

Should the devoted situationist then revert to depending upon the incentive "to love" in order to gain sufficient moral guidance (and justification), a further dilemma seems bound to creep in. This dilemma directly involves the concept of responsibility. Kolnai (1970: 252) explains

that "what we ordinarily mean by responsibility is precisely the testability, 'checkability', appraisability, judgeability, or shall we say the ethical intelligibility of an agent's conduct in terms of recognised (though not, in general, strictly definable or exhaustively enumerable) moral norms and standards of value". Yet, it is exactly "*against* this concept of moral discourse and arguable appraisal that situationism is directed, placing as it does – reservation made for 'love' – all emphasis on the agent's 'freedom', not in the sense of free-will or of 'freedom under the Law' but in the sense of a sort of moral 'sovereignty', i.e. freedom to 'decide' *in actu* what *for him* is *here and now* right or wrong to do". Clearly, the problem here is that, short of certain very simple and blatant cases of good-doing or evil-doing, nobody could on such presuppositions form a reasoned judgement on the behaviour of a fellow moral agent. A researcher, as a moral agent, would then be "above moral judgement", so to speak. And this is a problem, because how is a researcher's actions then to be evaluated and how, more importantly, is the researcher to be held accountable for such actions? Indeed, in accordance with situationism, any fellow moral agent is basically precluded from analysing the moral integrity of another's actions. There is simply no way of applying categorically tangible properties such as right and wrong to another agent's actions, since in the name of love "almost everything can be 'justified'" in this situation (Kolnai 1970: 252). Situation ethics thus offers only an impaired concept of responsibility that fails to provide any valid way of judging the moral content of an agent's chosen course of action. Worse yet, the agent may be deprived of a "seriously applicable moral orientation and make havoc of the conceptual scaffolding of his conscience" (Kolnai 1970: 254). Thus, the agent who lingers beyond judgeability in terms of moral categories may also simultaneously find him- or herself in a void of moral orientation.

In sum, situation ethics emphasises the undeniable fact that moral dilemmas are rooted in the complexity of the situations in which they occur. Hence, as these dilemmas often refuse any easy solution, there is a temptation to apply a set of ready-at-hand moral principles or to simply discard all such principles. Situationism wants to remedy this imperfection and attempts to do so by inflating the moral agent into a seemingly godlike creature who is capable of such extraordinary love that categories of judgement become superfluous. To promote such imaginary perfection is, for Kolnai (1970: 270), an approach "which is indefensible on all counts and has nothing to commend itself". This severe conclusion clearly shows that the strongest virtue of situation ethics – its recognition of the situational context of moral dilemmas – is sadly corrupted by the naive ideals it harbours for the ordinary moral agent.

Relational ethics

Feminine ethicists such as Gilligan and Noddings as well as their feminist colleagues Baier and Sherwin have advanced the relevance of social and emotional relationships to questions of morality (cf. Tong 1993). While each ethicist calls attention to a different dimension of such relationships, they essentially address a similar theme which I will discuss here under the heading of "relational ethics".

Relational ethics is fundamentally based upon the understanding that the moral agent is a social being constituted, in essence, by his or her relationships with others (Fontinell 1970: 211; Usher 2000: 24). Noddings (in Tong 1993: 115) frames this belief by saying, "It is not just that *I* as a preformed continuous individual enter *into* relations; rather, the *I* of which we speak so easily is itself a relational entity. I really am defined by the set of relations into which my physical self has been thrown". The relational ethics would thus concur with Smits (in Fontinell 1970: 208) that the moral agent, in fact, *is* relation.

Within relational ethics this fact – that the moral agent is constituted by relation – has crucial bearing on the moral decision-making process (Fontinell 1970: 212). In this process, it is the moral agent's human (that is, emotional or caring) relationships that give rise to all moral obligations. In accordance with such obligations, the moral agent should seek to preserve relationships and avoid harm to those cared about (cf. Noddings in Warren 1997: 137; Usher 2000: 29). While such an orientation should take precedence over adherence to abstract moral principles, it does not necessarily demand an abandonment of all moral principles. Instead, it suggests that "we give equal time to the other moral 'voice', which speaks not of principles, but of caring" (Warren 1997: 75). In other words, while the relational ethicists would be willing to consult moral principles, he or she would do so for the purpose of determining the best means of meeting the needs of those for whom he or she cares. Clearly, the primary motivation here would not be obedience to moral law, but rather to care, to remain related (Glen 2000: 18-19; Warren 1997: 138).

Through such a clear emphasis on the caring quality of relationship, relational ethics introduces into the moral realm the dimension of emotion. This evidently represents a reaction against the more traditional ethical approach that declares that the rights and wrongs in a situation can only be discerned once the agent has distanced his or her Selves from all personal emotions. Supposedly, emotions would not only fail to help the agent in moral decisions, but would also prevent him or her from finding the "right" moral path to follow (cf. Tong 1993:

73; Warren 1997: 138). So, for instance, utilitarianism would demand of moral agents to objectively weigh the interests of those they care about against the interests of those they do not know or do not like. No differentiation should be made about those cared about and those not cared about. No emotion or personal involvement is allowed to enter moral deliberation.

Admittedly, there is something very appealing about the thought that a certain blindness to personal emotions can bar moral agents from practising unjust favouritism. Still, for Blum and others (cf. Tong 1993: 74), traditional approaches have gone too far in condemning emotions. Moral obligations and decisions cannot be understood in isolation from the human feelings of moral agents. The simple fact is that moral agents (including researchers) do have stronger ties with certain Others (such as family and friends) than with all people in general. For Warren (1997: 76), "this psychological fact does not suggest that our moral concern should extend only to beings with whom we have close social relationships. But it does suggest that it is not always irrational for human beings to show special concern for members of their social communities".

Yet, while highlighting the important contribution of emotional engagement to moral deliberation, relational ethics appears to be plagued by a number of troubling questions. Firstly, according to Tong (1993: 124), Hoagland finds a relational ethic based on care particularly problematic when it involves unequal relationships marked by a measure of dependency. Can it be permissible for the "one-caring" to control the relationship with the "cared-for"? Is the researcher entitled to exert full control over the relationship, or the participant? After all, the researcher, as the "one-caring", certainly does not always know what is best for the participant, the "cared-for". In fact, very often, the participant is the best judge of her own good (cf. Tong 1993: 124). Hoagland reasons that as long as we choose such unequal relationships – that is, relationships in which one party controls its dynamics – as the paradigm for an ethical system, we propagate, rather than overcome, problems of power. Hoagland (in Tong 1993: 124) comments that "we live in a society premised on dominance and subordination, and oppression emerges in may forms – from parental all the way to colonial relationships – when decisions are made 'for another's own good'". Any ethics based on the powerful "helping" the powerless is an ethics rooted in some people telling other people what to do and how to do it. Can such an approach to ethics be acceptable? Hoagland believes it is not. To the contrary, ethics that would be seen as moral must be able to challenge (rather than endorse) those hierarchical ways of being, thinking and acting that leave others vulnerable to arbitrary uses of power (cf. Tong 1993: 124-5).

Secondly, Tong (1993: 94) shows that relational ethics is vulnerable to the accusation that it demands too much of the (caring) moral agent. It seems to almost deliberately instruct persons to give until they can give no more – that is, to sacrifice the Selves in the name of care until all physical, psychological, and spiritual resources have been depleted. Can this be morally acceptable? Is the participant indeed entitled to unconditional, unfailing attention from the researcher? Or is the researcher also entitled to some care? Can a relationship so askew in terms of "giving" be morally good? And can it constitute the basis for a sound ethical approach? What is more, if relational ethicists, in their ardour to promote caring relationships as a morally ideal grounding for action, venture so far as to forbid all forms of distancing, they are bound to invite even more serious problems. Such a state of obligatory emotional engagement with *all* others would not only impose severe demands on the entire being of moral agents. It would also threaten to render them unfit for decision or action of any sort (cf. Tong 1993: 65). Thus, an excessive commitment to caring engagement may, in effect, compromise the ability of moral agents to indeed act morally.

Thirdly, Tong (1993: 94) is of the opinion that a further common objection to relational ethics is that it supports a certain set of "psychological traits" or "values". That is, it appears to put a premium on possessing a certain type of personality, in particular, a kind and caring one. But what about the less empathic personality? Should such a person be excused from moral obligations? Surely not. In addition, what happens where empathic capacities fail the moral agent or have no opportunity to come into play? What if a researcher finds a participant so obnoxious that genuine care is out of the question? Or what if the research relationship is of such a brief duration that care has no chance to develop? Would the researcher be excused from moral obligations? And the participant? Indeed, without the moral guidance offered under the auspices of "caring", where should moral agents turn? Warren (1997: 145) points to the work of Manning who suggests that to be morally sound any relational ethic of care must provide some "standard" moral guidelines as a minimum below which behaviour should be morally condemned. Such guidelines, Manning (in Warren 1997: 145) argues, offers the necessary guidance in cases where empathic capacities flag for whatever reason. In Manning's view, such minimum guidance would also enable moral agents to extend their caring in important ways. For instance, minimum guidelines can be used to deliberate how best to care about others with whom moral agents do not share direct contact. Under such circumstances, "our actions cannot be guided by the expressed or observed desires of those cared for... In these cases we must make assumptions about their desires, and we can assume that they do not wish to fall below some minimum standard" (Manning in Warren 1997: 145). That is, should

a researcher fail to develop genuine care towards a participant, it would not spell the end to morally responsible action. The researcher would still have a minimum standard, a fundamental moral standard, to depend on. Of course, "in an ideal world, we might be so strongly responsive to the needs of other beings that we would have no use for minimum moral standards. But the world is imperfect, and so are we" (Warren 1997: 146). In the light of this, respect for certain moral standards does not become a substitute for active caring, but, given our deficiencies as "perfect" carers, "the world would be worse without these minimum standards" (Warren 1997: 146).

Thus, the human capacity (and perhaps the need) to care about others helps to both explain and justify many of the judgements that moral agents commonly make about their responsibility in the face of a moral dilemma. Yet, in fully conceptualising this responsibility, moral agents should not be bound by the limits of their empathetic capacities or by the boundaries of their immediate social communities. Social relationships do shape their moral obligations towards others, yet not to the exclusion of sound moral principles. It is rather more likely that empathic concern for others as *a complement to* the desire to follow sound principles will be able to provide morally good reasons for responsible action (cf. Glen 2000: 19; Warren 1997: 143-7).

Discussion

Throughout my study, I found that the interview – the direct personal encounter between researcher and researched – presented that area of interaction in which the researcher most directly confronted troubling moral dilemmas. During these interviews, participants were strongly encouraged to recount their stories about what it is like for them to have ME in terms of their situations, relationships, actions and meanings. However, the interviews not only presented a situation through which a story about severe illness was constructed, but also through which the actual nature of this illness became apparent. At times, participants indeed found the interview so strenuous and exhausting that the termination of our interaction became a very real possibility. It is on this critical interview situation that the following illustration and reflection on the different ethical approaches are based:

At the time of my first interview with Cheryl, she was extremely ill. So, while I settled into a chair, Cheryl was painfully manoeuvring into bed right next to me. Despite her obvious discomfort, Cheryl insisted that we should continue. But the result of her brave insistence soon followed. Cheryl's arms and legs grew stiff in one position, forcing her to painfully move them into another. The bed covers irritated her skin, leading her to lift them ever so often from one or another part of her body. Sometimes, she lost her track of thought. Often, she lost words. Throughout, I was plagued by the obvious concern: should we continue or would it be better to call it a day? Based on the participant's insistence, the interview did continue. By the end of our session Cheryl could only move very slowly and was complaining of a pounding headache. She had literally willed her way through the interview, yet now had to bear the consequences. I, in turn, was left with the nagging question: was the decision to continue the interview the most morally worthy course of action to take?

Cheryl's strong-willed determination to continue at all odds also marked our second interview and its consequences. Cheryl suffered gravely, so much so that by the end of our last session, she was hardly able to move, complaining that she had stiff and painful 'knots' in her muscles. Her voice was on the verge of shaking when she spoke and, she confessed, her eyes had stopped focussing quite a while earlier and she could only see me as a blur. We slowly made our way to the front door, where her husband joined us. There, she clutched his arm with both her hands to steady her increasingly unsteady body. It had by then become (disturbingly) obvious that our session had provoked a serious relapse. As I drove home, I was again plagued by the nagging question: was the decision to continue the interview the most morally worthy course of action to follow? Or was there a different – better – way to complete my research interviews?

This was the pattern that emerged during many of these research interviews: participants insisted in persevering despite their own suffering and resisted numerous offers to postpone our meeting. Each time I yielded to their determination, only to see them suffer the consequences of their brave effort. And while their suffering and their insistence spoke of the several critical themes in the study (such as their inability or unwillingness to admit to obvious physical limitations), this realisation did not make it any less difficult to bear, either for them or for me. After all, the point of my study was to help ME sufferers, not to induce another

week in bed! Given this turmoil, I sought to find answers among those traditions which claim to have them…

In a situation such as described above, having assumed a utilitarian perspective, I should have asked: would the "harm" endured by Cheryl be outweighed by the "good" to follow from a more in-depth understanding of the illness experience? Or would the "good" procured in the process not be sufficient to justify the "harm" endured by her? Up to a certain point a utilitarian perspective resolved my moral dilemma. I could, after all, recognise that moral conduct, at least in one sense, would imply a course of action conducive to the (most beneficial) interests of the greatest number (cf. Kolnai 1970: 248). Armed with this recognition, I could decide that as "the greatest number" – that is, society in general as well as the ME community itself – would benefit from a better understanding of ME, the interview (which is directed to this end) should continue.

Still, I had a problem, even several: on the "harm" side of the ledger sheet it was difficult to calculate whether any human suffering would occur, how severe it would be, and what relative significance it would have. For instance, was the harm endured by Cheryl's family as a result of the prolonged interview truly less significant than the potential good procured by means of a better understanding for society as a whole? By what scale was I - not the participants - supposed to weigh the good of a few against the good of many? Moreover, how certain could I be that any "good" would actually be realised?

These questions are particularly pertinent in such an incredibly sensitive area of research, with a topic charged with emotion, loaded with moral meanings and carrying a burden of stigma. What exactly would constitute a benefit within this context is not clear and consensus on it is unlikely. In support of continuing the research interview some might argue that in many instances, particularly in sensitive areas, research participants desire catharsis rather than sanctuary. And as catharsis can only happen through the medium of the interview, the latter should continue. In this way, the interview may produce not only gains in knowledge, but also effects that are directly beneficial to the research participant. In contrast, others might argue that academic research of this kind is severely exploitative – taking advantage of the participant's need to talk to the detriment of her physical well-being. Under such conditions of violation, there can be no question of sanctuary. Hence, the interview should be terminated. While perhaps aware of such different arguments, the final decision still remains the

researcher's. And with very little guidance on how to differentiate between the applicability and credibility of such arguments, the researcher is no closer to an adequate response.

There is still a further problematic repercussion of utilitarianism which Tong (1993: 64) calls "failures of moral imagination". Wheatly refers to a "flexibility of mind" (in Usher 2000: 34) that seeks to actively explicate the conditions and contexts that frame a specific context. Where it is lacking, the moral agent fails to focus on the implications of *this* situation and the plight of *this* person. In other words, I would ignore or not notice the pain in Cheryl's eyes or the tremble in her voice. This would make it easier for me to "sacrifice" the well-being of one person for the sake of "the common good". Yet, to so readily "sacrifice" a flesh and blood person in the name of a "large-scale goal" that will somehow benefit "the greater good" is, at best, a morally dubious tendency, and at worst, an altogether morally blind one.

With utilitarianism then offering little help in resolving my moral dilemma, I may have turned to deontology. A deontological approach would have demanded that I terminate the interview. I would do so, firstly, out of respect for the participant and, in particular, for her state of health, and secondly, in view of the deontological commitment not to treat another person as a mere means to some greater end. In short, because it would be my duty to respect Cheryl as a person, I would summarily call a halt.

To provide the individual – in this case, the participant – with strong moral rights which must not be violated may be one of the most important contributions of a Kantian deontological approach to ethics. Indeed, for Warren (1997: 101), a moral theory that demands categorical respect for the moral rights of the individual is "truer to the convictions that most of us hold than one that permits those rights to be sacrificed to the goal of maximizing utility". It is also, Warren adds, "truer to the spirit of the Golden rule, which speaks not of maximizing total happiness, but of treating other persons as we would like to be treated". Thus, instead of advancing maximum good by developing a greater understanding of ME to the detriment of a participant I, as a deontological researcher, could have ended the session and so safely avoided any further morally compromising repercussions.

Yet, while the strong emphasis on mutual respect for moral rights that such a course of action reveals is highly commendable, the deontological approach is, as we have seen above, clearly not without its problems. Here the possibility of becoming a "morally lazy" researcher is of particular concern. Tong (1993: 22) for instance, notes that, because deontologists stress so

strongly the abstract and absolute character of moral rules, they "struggle to adjudicate so-called 'conflicts of duty'". To be sure, deontologists could argue that one or the other of seemingly conflicting rules "is not really absolute; or that God would never permit two really absolute moral rules to conflict; or that a moral rule is absolute only in the 'abstract' and not in the context of certain concrete circumstances" (Tong 1993:22). Clearly, these strategies do not truly offer any solution. For instance, what if I could not but notice how Cheryl's suffering appeared to escalate as the interview continued but insisted on proceeding? What would the deontologist do? What would I, the deontological researcher, do? I could choose to respect the integrity of the participant's body in order to prevent (further) damage. But would this not verge on the paternalistic – making a decision *for* the participant about the participant's own body? Alternatively, I could choose to respect the intrinsic value of personal autonomy and not question the participant's personal decision. This would assume that the immediate illness experience has left the participant's decision-making capacity untouched. This is something I could neither know with any certainty nor judge without a sense of paternalism. After all, is respecting the participant's capacity for self-determination not in true Kantian terms a way of expressing respect for her dignity as a morally autonomous being? The deontological approach appears to have little answer to concerns of this kind as it clearly does not enable the researcher to prioritise either *genuinely absolute,* or *conflicting* moral rules.

Both of these approaches – utilitarianism and deontology – appear to be based upon an assumption that, since it is not possible to consider all the factors involved in any situation, the only way to avoid destructive relativism and scepticism is to isolate some general laws or values which remain basically untouched by the context in which they enter. As a result, these traditional approaches to ethics and ethical decision-making reveal a rather unsatisfactory tendency (even temptation) to resolve ethical questions in the abstract or in terms of (universal) absolutes (cf. Fontinell 1970: 209).

More recently, these two traditional approaches to ethics and, in particular, their abstract and universalising tendencies, have increasingly come under attack (Usher 2000: 29; Warren 1997: 138). The voices of situationists as well as feminine and feminist ethicists appear to be the most influential in this context. Both situation and relational ethics demand that, above and beyond any set of abstract moral principles, it is the unique situation as well as the individuals in it that should take precedence in the face of any given moral dilemma (Simons & Usher 2000: 2-3). It is exactly this bold (and, in a sense, balancing) critique of more traditional

ethical theories which brought the potential contribution of situation and relational ethics to my attention and so required their incorporation into my ongoing ethical reflection.

In the situation described above, I would – in terms of situation ethics – not be bound by any specified rule or standard about the kinds of action that would be obligatory or forbidden, commendable or condemnable. I would simply be encouraged to focus on the concrete as opposed to the abstract, that is, to openly recognise the unique or particular features of those persons or situations about which a moral decision needs to be made. I would thus be free, for instance, to terminate the interview session provisionally and to first discuss the implications of continuing with the participant. In situationist terms, such a course of action would tell of no strict adherence to any 'ready-made' universally applicable moral guidelines; yet, it would be equally fitted both to this unique situation and to the interests of this particular participant.

But what would determine the "moral good" of the action taken? The dedicated situationist would presumably seek guidance in the demand to "love". It would indeed appear that, in essence, the situationist approach boils down to a notion that whenever an act is done in social attitude of "love" such an act is "good" (cf. McCabe 1970: 68-70). This then would be the extent of moral guidance offered under the auspices of "agapéic love". But would such guidance not imply that human acts receive all their "moral goodness" solely from the intention with which they are done? Could every action done in love be labelled morally good? If I had, out of sheer concern, insisted that Cheryl stop talking immediately, would it be morally good? Would it not perhaps be erosive of Cheryl's autonomy? What is more, are there not some things one should never do, not even in the name of love? Had I, again out of sheer concern, insisted that the participant should there and then plot her own suicide as this would surely put an end to her misery, would that be morally good? Or would it rather be malicious and evil? While these examples may appear to verge on the ridiculous they do serve to make the point: aiming towards the highest and most fundamental 'motivation' – that is, agapéic love – does not exempt the ethical thinker (nor of course the researcher) from the task of closely probing the meanings of morality and of differentiating the praiseworthy from the morally mediocre and, more urgently, the permissible from the wrong (Kolnai 1970: 256).

Finally, in the instance described above, what would the relational ethicist have asked me to do? The caring relationship with Cheryl should have motivated me to respond to the perceived need and to show "special concern" for the well-being of the participant. Cheryl is, after all, not some abstract Other; she is a concrete human being – someone I have come to know and

care about. Under such circumstances, it may very well be inappropriate to demand that I should assess the moral dilemma independently of my feelings for those who are affected by my actions. Moral deliberation does fall under the influence of emotion. To ignore the concrete reality of this influence in favour of some abstraction such as absolute equality (of say, all participants) may be not only impossible, but also undesirable (Gruen in Warren 1997: 76-7).

Acknowledging such a relationship of care within the research context, I could have opted to discontinue the interview session. This would have served as an expression of care, showing that I only have the participant's best interests at heart. However, it is also possible that such a course of action might reveal more about my own sense of "being in debt" than of any true sense of care for the participant. That is, by focusing exclusively on "care", a researcher could, almost inadvertently, allow him- or herself to be burdened by a never-ending feeling of 'being in debt' towards participants (the "cared-for") who so unselfishly gave of themselves for the purpose of research. Under such circumstances, the researcher would be held captive by a misplaced feeling of debt from which he or she somehow cannot be delivered and in the name of which he or she should comply with every reflex to "return the favour".

Furthermore, while based on sheer concern for Cheryl's well-being, such a course of action may well have supported an unequal relationship between researcher and researched. Indeed, would I not in this rather paternalistic way assume full control over the course of interaction, over Cheryl and her participation? And how was I, as the "caring" researcher, to discern when exactly her interaction was truly becoming too taxing for her? Even if Cheryl did signal exertion, I might not necessarily have been sufficiently sensitive (or even receptive) to this message. Clearly, morally responsible action cannot rely on emphatic concern alone. Rather, a more complete interpretation of the I as a relational entity suggests that such concern should be supported through ongoing interaction between the researcher and the participant to foster a sense of shared responsibility for the ethical character of the interview situation.

Thus, my study served to reinforce an awareness perhaps common among but not often enough explicitly stated by fellow social researchers: that no single moral principle can help us resolve our moral dilemmas. I recognised that no single approach that emphasises a dominant moral principle – be it utility, duty, situation or relation – could account for the immense range of elements involved within any given moral dilemma. Given the limited scope of such single-criteria approaches, I identified the need to consider a more integrated, more encompassing

approach to ethical decision-making. This now leads me to argue in favour of a kind of "ethical eclecticism" (Warren 1997: 242) which I perceive as far more likely than any of the other single-criteria approaches to help us deal competently with the moral dilemmas encountered in social research.

Conclusion

Like Sartre (and eventually perhaps also like Sartre's student), I too have realised through the course of my study that solutions to the ethical problems of life *and* of research are in no sense given. They cannot be found at the back of the book like the answers to mathematical questions. In fact, any blind belief in given resolutions will only serve to conceal the extent to which we must engage in conscious deliberation and reflection if we are to reach any satisfactory solution to vexing moral dilemmas.

The need for – or necessity of – such reflection was clear throughout my study during which I consulted many traditions of ethical thought. Each of these traditions has endeavoured to identify those ultimate moral principles that will be able to guide our actions. In their efforts to advance their own moral rationale, these traditions have presented moral principles which emphasise such values as utility, duty, situation, and relation so forcefully that they (at least at first) seem to be wholly irreducible, even absolute. Yet, such principles and their values are not somehow "given" or "imposed" upon human life (or for that matter upon the researcher) from without. Instead, as Dewey (in Fontinell 1970: 210) suggests, they have developed out of the very operations and needs of human life itself. Hence, inasmuch as human life is continuously open to change and modification, so too are the principles and values to which it gives existence. This means that while a framework of moral concepts may be as permanent as human life itself, the moral concepts which it contains carry in themselves no absolute certainty. Such moral concepts do not have "a privileged position of being beyond review and criticism. No values are protected from critical scrutiny and reinterpretation on the basis of developing thought and experience. All values must continually be capable of being not merely asserted, but justified in the human community" (Fontinell 1970: 210).

Thus, far from mechanically accepting the principles and values of any handed-down morality, I set out to reflectively engage with and critically scrutinise those principles advanced by a collection of pertinent ethical traditions. In my efforts to do so, I (re-)discovered that no single

moral principle can provide any real guarantee of ease in the resolution of practical moral dilemmas. No ethical theory dominated by a single moral principle can present all the relevant considerations to the moral agent. In fact, an exclusive focus on one principle of moral responsibility is likely to result in a tendency to confine the moral outlook to what is easier (or more convenient) to notice, to codify, and to apply. While allowing the moral agent to act without indecision, such an approach is not truly helpful. On the contrary, the "single-mindedness" of one presiding persuasion all too often transforms into an uncomplicated "simple-mindedness" (Glen 2000: 21) where the moral agent's deliberation fails "to match the world as it really is" (Williams in Glen 2000: 21). Such a state of mind easily becomes tinged with an air of comfortable self-righteousness and can only be conducive to an all too mediocre, trivial and inadequate conception of morality (cf. Glen 2000: 14-5; Kolnai 1970: 241).

I therefore am of the opinion that any attempt to make valid judgements about moral activity based solely on a single principle is bound to distort my sense of moral responsibility. However, rejecting the use of a single principle does not necessarily leave me stranded, for I agree with Warren (1997: 22-3) that an account of moral responsibility which accommodates a greater diversity of insights drawn from a number of ethical traditions is likely to prove far more useful in research practice than one that appears to pursue theoretical simplicity at all costs. Only such a multi-criterial account of our moral responsibility can incorporate the sound ethical considerations that underlie each of the single-criterial theories, while avoiding the obvious distortions they may individually introduce (cf. Usher 2000: 37; Warren 1997: 177).

An approach that permits us to integrate those diverse factors that shape our moral responsibility represents a step towards what Warren (1997: 242) calls "ethical eclecticism". This approach does not centre on any one aspect of a moral dilemma in isolation from other aspects. Rather, it acknowledges and engages with the values of both the abstract and the concrete, the universal and the particular, the impartial and the emotional, the individual and the relationship. While not all these properties that constitute the totality of a moral dilemma will always be equally important, not one of them need to be elevated to the exclusion of the others. On the contrary, what would determine the most morally sensible course of action in the face of a practical moral dilemma is the conscious and critically reflective weighing and evaluation of the diversity of pertinent properties and principles that may have a bearing on the particular situation (cf. Glen 2000: 14-5). In the process of doing so, of taking a step towards an ethical eclecticism, we as researchers become able to avoid the aura of certainty (and the

concurrent demand for unyielding commitment) that surrounds seemingly absolute principles. We instead attend to the diversity of properties and principles in a particular situation, evaluate their relative weight and importance, and then act decisively. At the same time, we remain open to the discovery of new features, and willing to review our assessment of the situation in the light of ongoing experience (cf. Fontinell 1970: 213).

While I may speculate that to so take account of the astounding complexity of a moral situation represents a preferred way to advance from appreciating the good to actually doing it, I must concede that it is not an easy task, neither to describe nor to perform. Still, its demanding character does not excuse us from taking a stand, let alone permit us to simply follow our whims. Thus, despite the fact that we can have no absolute certainty, we must reflect, decide and act (cf. Usher 2000: 36). In so doing, even the most exhaustive listing of relevant properties and principles will not in itself result in an ethical decision. After all, there can be no question of moral responsibility if ethical decision-making simply involved a kind of deduction derived from premises pre-given by society (cf. Cunningham 1970: 11; Simons 2000: 39-40). There is obviously no substitute for personal deliberation and reflection, albeit of the sort that will almost invariably be tinged with a certain tentativeness, even "undecidability" (Usher 2000: 36). In this sense, Fletcher (1970b: 276) may very well be correct in asserting that "in the last analysis, one's ethics comes down to a decision, not a conclusion; it is a matter of faith posited, not of fact verifiable empirically".

In the light of its timidity, the multi-criterial approach suggested here may appear to many as too tepid and hesitant. To a degree this perception is true for I certainly do not confidently claim to offer a perfect (let alone instant) resolution to every vexing moral dilemma. In fact, a controlling presupposition for me, as for Sartre, is that there are no absolutely definitive resolutions for life's most troubling moral dilemmas. Yet, I do believe that a step towards ethical eclecticism may well enable us to deal more constructively with such dilemmas, even if only by leading us to recast them in such a way that certain blind alley resolutions are once and for all avoided. What is more, a step towards ethical eclecticism may also put us on the way to more fully re-conceptualising our approach to ethical decision-making within the social research context. Such a re-conceptualisation – mediated by a commitment to practical relevance – must be undertaken to provide research ethics with a workable, defensible model of ethical decision-making in challenging research situations. I submit that it would be fruitful to start this process with ethical eclecticism as a point of departure.

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Chapter 20

Research description: "What went on here"

For Tait (in Stark 1998: 212) "what all of us who write produce simply stands as the version of 'what went on here'". Within the context of social research, the production of such a "version" – as the researcher's final description – represents a complex process that involves the transformation of participants' stories into the pages of written research findings.

In this study this process of transformation was very deliberately not based on a conception of participants' stories as some "internal representation" (Pollio et al. 1997: 28) contained in the mind of a participant just waiting to be externalised and represented by the researcher. I did not seek to "externalise" anything for that would imply that I was looking for one (more or most) truthful version to be captured without adding too much bias in the process. I did not regard the ways through which my participants chose to describe their experiences as distorting, nor did I consider myself an intrinsic source of error. Had I proceeded otherwise (more "conventionally" perhaps), I would have chased in vain after the unrealisable fiction of "absolute truth". What is more, I would have taken the risk of wholly missing the very focus of my study in the presentation of its findings: concrete human experience.

For me, as for other researchers like Pollio et al. (1997: 31), there is no question of retrieving some "internal representation" which could somehow be directly reflected on the pages of the researcher's text. Internal representation is but a chimerical entity. As an alternative I choose to regard all understanding as constructed through social discourse. In this way, I can recognise the participants as the "producers", as the ones who tell or perform their personal stories. And I could recognise my own role as "coaxer" of stories, as the one who persuades and invites these personal performances (cf. Barbour & Huby 1998: 12). It is through the relationship between the producer and the coaxer that a life story becomes constructed around specific events and happenings. It is this relationship which harbours the meaning the coaxer wishes to pin down in words in the written research text.

The description constructed through the research relationship is, very much unlike any rigid internal representation, no dull static entity. It is a dynamic story in which the social and the personal fuses in complex and multiple ways – and in which the researcher's self plays a critical role. Here, the researcher not only serves as the "protagonist in the exchange of tales"

(Barbour & Huby 1998: 12). The researcher also reflects, and reflects upon, and actively contributes to the production of the final description – of the version of "what went on here".

The remainder of this chapter is dedicated to the development of a better understanding of this social process of interaction and construction through which the research description is produced. In doing so, I hope to explore and lay open the specific ways in and through which I came to interpret and describe the unique human experience that I studied.

Establishing "out-there-ness"

Heaphy (1998: 31) acknowledges that the academic disciplines in which we operate play a crucial role in defining the appropriate methodological approach. For the most part, the social sciences are marked by the legacy of "objectivity" that is central to scientific claims of expertise and the "privileged position" of the knower. Here, objective knowledge is regarded as consisting of general mental representations which obtain their meanings exclusively through their capacity to correspond to the external world. Objective knowledge representing real world events has priority over personal experience in which representation of inner states cannot be excluded. Thus, it is not what I feel or what I experience that counts, but rather "how things are".

A perspective that stands firmly in line with this positivist legacy is contained within the position of a "disinterested observer" (Schutz 1962: 137). For Schutz (1962: 63), the researcher wishing to adopt the perspective of a disinterested observer is never present in his or her private capacity and should in no way become involved as such in the research situation. After all, this situation is, for the truly disinterested observer, "merely of cognitive interest".

In effect this approach implies that all aspects of the researcher's very being undergo a fundamental modification (Schutz 1962: 63; 248). The researcher as disinterested observer replaces a personal (practical) structure of relevance with the more theoretical interest of the research question. The selected scientific problem *alone* determines what is relevant for the researcher as well as the conceptual frame of reference guiding the researcher. What is more, the researcher as disinterested observer also endeavours to replace the personally constituted biographical situation with what might be called a "scientific situation". The researcher has now abandoned all "essentially actual" experiences that have been characteristic of life within

the naïve ("non-scientific") "natural attitude". To complete this transformation into the ultimate manifestation of detachment, the researcher attempts to bracket the entire conglomerate of social and physical experience. Indeed, every part of the researcher's existence, of the self, is to be bracketed – suspended, placed "outside". This is what Husserl (in Schutz 1962: 104) advocated as the "phenomenological reduction" of all possible sources of conceptual bias that may distort the researcher's interpretive vision.

So the researcher striving to attain the status of "disinterested observer" becomes a theoretical thinker with no physical environment, as there is no longer any section of the world within immediate reach. More importantly, the theorising self is also a solitary unit, standing outside all social relationships (Schutz 1962: 253). What remains after the performance of such "transcendental reduction is", according to Schutz (1962: 105), "nothing less than the universe of our conscious life, the stream of thought in its integrity". This, the pure stream of thought, is then regarded as the "ideal" (read: the least biased) perspective from which the researcher can proceed to interpret.

There is, however, a problem (possibly several) with the approach personified by the "disinterested observer". For, as Pollio et al. (1997: 47) recognise, complete bracketing is simply impossible to achieve. The researcher (as any other human being) simply does not know the self well enough to bracket every possible presupposition, belief, and preconception, not to mention emotion, passion, impression and affection. The demands made of the researcher by this type of bracketing clearly goes far beyond what is humanly attainable.

Despite this researchers, still striving (knowingly or unknowingly) to realise the positivist ideal of the disinterested knower, have ingeniously learned to portray themselves as privileged knowers in the constructions and presentations they offer. Hence, when researchers present the research process in a reconstructed form they (are encouraged to) do so in a way that will strip their "self" from their descriptions or describe their involvement in ways that will testify to the necessary distance between their "self" and the social world they claim to present.

One of the most basic ways through which to put the social reality that is being studied outside all human agency – and certainly outside the researcher's influence – is by employing a grammatical device that excises the producer from the description – rather use "it was found that..." instead of "I found that...". Another way of creating the illusion of sufficient detachment involves the deliberate construction of consensus and corroboration by presenting

a conclusion as a shared one ("we argue..."), instead of being unique to one ("I argue..."). Descriptive passages of this kind certainly prevent attempts to discount them as the product of one particular person. Another familiar form of constructing "disinterest" and "detachment" works in a rather different, almost contradictory way. This involves detail and narrative that fashions a story or a scene so "real" and so remarkably vivid that the reader feels as if he or she had "observed directly". The reader is, as it were, pulled into the scene and put there in the place of the researcher.

Together, these "externalising" approaches fall under the banner of "out-there-ness" (Potter 1996: 150). These procedures deliberately draw emphasis away from the nature of the producer by constructing the description as independent of the agent doing the production. It is in this sense that Latour and Woolgar (in Hacking 1999: 81) make the interesting point that "out-there-ness" is "the *consequence* of scientific work rather than its cause". While this is not to say that there is no "reality", it does serve to emphasise that what we say about it is in a sense made, constructed, so as to *appear* independent of the constructor.

Traditionally, this very effect of "out-there-ness", as engendered through the use of externalising approaches such as those described above, have been a significant source of power behind researchers' voices. Through presenting themselves as truly disinterested observers in the descriptions they produce, researchers have indeed been able to write about the experiences of others as though these are directly available to them. However, in doing so, the powerful position (or illusion) of "disinterested observer" also deceives the reader because it obscures the fact that these very experiences are inevitably transformed by the researcher's very construction of them. As a result of this obstruction, the reader does not know and, hence, cannot question how or why the researcher, who remains hidden, claims to know what he or she does (Stanley and Wise 1993: 155). For Heaphy (1998: 31), the danger involved in the construction of "out-there-ness" goes further than deceiving the reader. He argues that when we so eagerly "edit out" our own voice, we may very well easily become silenced in other respects of the research endeavour as well. And we may not even be aware of it.

Based on this view, Stanley and Wise (1983: 195; 1993: 166) strongly urge researchers to avoid the perspective afforded by the position of "disinterested observer". Researchers are, instead, encouraged to present comprehensive analytical accounts of how and why they think they know what they do about the research situation and the participants involved in it. Researchers should, in other words, be particularly concerned "with presenting *ourselves* and

our understanding of what is going on". "We must make ourselves vulnerable", Stanley and Wise (1993: 166) say, and "not hide behind what 'they' are supposed to think and feel, say and do". For Stanley and Wise, this approach re-introduces an appropriate (and perhaps long over-due) emphasis on the researcher's responsibility for the description produced. In addition, it also ideally enables researchers to reveal in their descriptions the truly contextualised nature of human experience and understanding that so often succumbs under the legacy of objectivity.

Many researchers have hesitated in embracing this direction which places such a deliberate emphasis on the role and influence of the researcher's self in the production of a written research description. Rosaldo (in Stark 1998: 210), for instance, wished to avoid introducing the self into the research account for fear of simply adding to a collection of "essays laced with trendy amalgams of continental philosophy and autobiographical snippets". Yet, according to Stark (1998: 210-211), Rosaldo himself found it necessary to introduce his own experience of grief to explain how the rage in grief compelled the Ilongot men to headhunt. Before losing his wife, he could not fully understand the force of anger possible in bereavement. The death of his wife however released in him feelings which he then came to recognise as those experienced by the Ilongot. He then felt in a position to revise his earlier understanding of Ilongot headhunting to include a focus on the anger and rage that grief provokes.

Rosaldo's personal experience was clearly extremely pertinent to his study of Ilongot headhunting. In a similar sense, my own personal biography is important in order to understand how the particular understanding I presented was produced. An undeniable part of my biography was (and is) my own illness experience. The awareness of a shared experience with my participants was almost always present – and specifically in the interpretation and description of the research data. This recognition confirms that "interpretation cannot begin from a tabula rasa" (Cohen in Stark 1998: 211). Hence, far from denying our presence and influence in interpretation and description, we must use all the resources of sense making that are available to us. Each researcher's "sense making" will therefore be different and very much dependent on his or her own set of personal experiences.

Seeing from a perspective

An acceptance of the researcher's self as fully part of the interpretation that is developed, at once demands a recognition that the way in which the researcher looks an Other's experience

would undoubtedly bear the mark of the knowing mind – the researcher's mind. Thus, what the researcher is able to see depends on how the researcher looks at what is given.

This fact – that the researcher interprets and describes an Other's experience from a particular perspective which is inevitably limited – stood out clearly in this study. During one particular interview with Helen, for a brief moment of rare insight, I suddenly just *knew* that I would *never* be able to fully comprehend what *exactly* had transpired during Helen (or anyone else's) experience of illness. I could perhaps (re-)construct glimpses of this experience, but I would never be able to grasp the full force, the impact, and the repercussions, of *her* illness. I would, in other words, never be able to *see* into her experience, into her being, as though I was simply looking through a pane of glass into somebody else's home. I would never be able to live through all the conscious states and meaning-endowing acts which constituted her experiences *for her* in a particular way. In short, I could never be the Other; I could never be Helen. What I saw would always be partial, incomplete and limited. This moment of insight sharply (and almost painfully) outlined the shortcomings of my own understanding.

Yet, recognising the limitations of my own comprehension of an Other's experiences should not necessarily entirely negate the possibility of ever understanding an Other's experience. Here, I choose to agree with Schutz (1967:99) when he argues that "we are asserting neither that your lived experiences remain in principle inaccessible to me nor that they are meaningless to me. Rather, the point is that the meaning I give to your experiences cannot be precisely the same as the meaning you give to them when you proceed to interpret them". So, as the Other's world is not given to me in a direct fashion, I cannot share the exact point of view from which the Other has conferred meaning onto the lived experiences in question. We are looking at these lived experiences from two different points of view; our perspectives differ.

Schutz (1962: 210; 1967: 69) explains that, within the world under the researcher's reflective gaze, the meaning of experiences is not an inherent quality of the experiences. Meaning does not lie in the experience itself. Instead, meaning is situated in the way in which the researcher reflectively regards the experience. In this sense the researcher, as the knowing mind, constitutes the very source of meaning. In Schutz's (1967: 73) phraseology, the researcher becomes the "Ego-ray" emanating its light – its meaning – over every given experience.

When the researcher turns a reflective glance to the experiences of Others to ask for their meaning, what is discerned depends very specifically on what Schutz (1962: 212) calls the researcher's "attention to life". This is the basic regulative principle of the researcher's conscious life, which both defines the realm relevant to the researcher and determines the attention directed by the researcher to the given experiences. The researcher's "attention to life" is, however, not a static entity. It is, instead, very open to modification and is capable of showing all sorts of shadings: from actual comprehending to merely noting to hardly noticing to leaving completely unobserved (Schutz 1967: 73-74). For the researcher, every moment in time – every Here and Now – is constituted by such attentional modifications. Consequently, the interpretation (or meaning) the researcher imputes to an Other's experiences depends on those attentional modifications marking the very moment of interpretation, that is, the actual Here and Now from which the researcher is looking.

Within the moment of interpretation, the meaning of a lived experience consists in the ordering of this experience within the total configuration of the researcher's experiences that is present-at-hand (Schutz 1967: 78-83). So the researcher's "schemes of experience" present in the Here and Now become the meaning-context to which all new experiences, once apprehended in the glance of attention, are referred. Schutz (1967: 83) refers to this process of referral as a "synthesis of recognition". For Schutz (1967: 84), this process of ordering lived experience by means of synthetic recognition represents the very gist of interpretation. Hence, the schemes of experience (the known) to which every newly apprehended experience (the unknown) is referred, in effect, become the researcher's "interpretive schemes" (Schutz 1967: 84). Again, these schemes cannot but bear the mark of the actual Here and Now through and from which the researcher's interpretive glance is operating.

An important component of the researcher's interpretive schemes, of the configuration of meaning that guide interpretation, is the researcher's presuppositions, prejudices, and preunderstandings. There is indeed no such thing as "pre-suppositionless" interpretation (Douglas 1970: 21). After all, as Heidegger (in Pollio et al. 1997: 349) points out, "any interpretation which is to contribute to understanding must already have understood what is to be interpreted". Moreover, any interpretation of lived experience requires the interpreter to bring to bear a particular frame of reference, a pre-understanding of the world. In this way, an interpretation is very much contextualised by the pre-understanding manifest in the interpretive situation (Pollio et al. 1997: 46). The active presence of pre-understanding certainly need not be regarded as a mere inevitable imperfection simply to be tolerated in the act of interpretation.

Neither need it be applied in a dogmatic or blinding manner (Pollio et al. 1997: 46). Instead, what it contains is the promise of a certain way of knowing, of making sense, of interpreting. And all that is asked of the researcher is to commit to a thorough explication of every pre-understanding operative within the interpretive context (Douglas 1970: 22). While such an explication can, of course, never be complete, it can nevertheless advance the researcher's interpretive scheme... and hence also the interpretation presented.

In fact, the researcher's interpretation changes through the explication of all pre-understanding, and through becoming more aware of the background that influences the researcher's perspective. In turn, as the researcher's interpretation changes, so the researcher's pre-understanding is modified by the (new) understanding gained (Potter 1996: 49). There exists, then, a continuous process of going back and forth, with "earlier" and "later" parts continuously being modified in the light of the unfolding understanding (Pollio et al. 1997: 51). The aim of this continuous process of revision and renewal is certainly not to establish some kind of "generalisability". Rather, it is to improve the researcher's interpretive vision.

Aside from personal pre-understanding per se, there is one more important – though often-neglected – component shaping the researcher's interpretive schemes and, hence, the interpretation presented. This component is highlighted by Harding (1986: 158-161) when she explains that the researcher's interpretive perspective has very much to do with the "bigger picture", with the greater historical influences operative at the time of interpretation. According to Harding's discussion, the researcher's interpretive schemes incorporate and reflect the shifts in social life that make a particular way – perhaps a new way – of understanding possible. In effect, these social changes serve as the preconditions for interpreting in a particular way, for producing a particular construction. And these social changes need to be located, because only then can the researcher's interpretation be fully regarded as an expression of the ways in which social life can be understood by a new kind of historical person.

Clearly, what follows from the active process of interpretation can never be regarded as a static, decontextualised, a-historical "thing-in-itself" somehow simply reflecting how things "really" are. Neither can it be reckoned as intrinsic to the experiences interpreted nor as a pure projection of the researcher's own world. Rather, as Pollio et al. (1997: 52) suggest, the researcher's interpretation seems better construed as a perceptual entity, a complex pattern afforded by the given experiences as well as by the researcher's interpretive schemes operative

in the actual Here and Now of interpretation. Also, as the researcher's interpretive schemes (and all their constitutive elements) are forever (in every different Here and Now) open to elaboration and modification, it can never be entirely exhaustive. This means, as Schutz (1967: 85) puts it, that "no lived experience can be exhausted by a single interpretive scheme. Rather, every lived experience is open to numerous interpretations".

Thus, the involvement of the self in the interpretive process demands a recognition that what I saw was very much a function of my self – of how I looked, of what I attended to, of the moment from which I looked, of my own sedimented experiences, of my own pre-understandings, and of my own socio-historical position. In short, I acknowledge that my interpretation and description followed from who I was in my own Here and Now. The self through which I had engaged with participants and through which I was now developing a description was socially and historically contingent. As a result of this recognition, I was in a better position to practically engage with the forces that had shaped my interpretation and final version of "what went on here".

Telling it like a story

The description I had produced (and am producing even now) can in no way be regarded as a neutral, transparent description of "reality". Description in social research, as Potter (1996: 218) suggests, can rarely (if ever) be regarded as a simple inconsequential aggregation of "facts". Rather, it is often very much like a story, a narrative marked by the conventions and limitations of the literary domain.

A critical part of the art of story telling lies in the way in which the story captivates (and convinces) its audience. To achieve this, researchers often opt for those quotations which, although typical in some respects, make the point more vividly, succinctly or humorously than do others in their store (Barbour 1998: 193). As Edmondson (in Barbour 1998: 193) explains, if "we regard such citations as rhetorical devices for enabling and encouraging readers to perceive the force of general remarks, we can expect examples to exhibit particularly concentrated cases of what happens generally but, perhaps, less remarkably". We thus use the "atypical to highlight the typical" (Barbour 1998: 193).

Here, as Barbour (1993: 193) notes, fine judgement is required. And we do not always get it right. In selecting quotes for presentation to one's peer group, one is perhaps on firmer ground. Steeped in a common literature, involved in similar theoretical debates, and familiar with the particular form of work, one is likely to better anticipate what would work for this audience. However, it is much harder to select appropriate examples, excerpts or quotes for other audiences, who may be unsympathetic to both the form (viewing our enterprise as "anecdotal" or "journalistic") and content (seeing our examples as sensationalist, unkind or indicative of an detrimental interest) of our work

Indeed, despite a plethora of methods texts bursting with advice on coding and analysis, there is, as Barbour (1998: 194) observes, "little practical guidance available on choosing examples for our oral and written presentations". In many cases, the selection of such material for presentation appears to be a matter of "taste", with all the graduations and subtleties which this implies. Given that this is hardly ever acknowledged, our writing may obscure far more than it reveals. For as Richardson (in Barbour 1998: 194) argues, the researcher often "writes the body of the text as though the quotations and document snippets are naturally there, genuine evidence for the case being made, rather than selected, pruned and spruced up for their textual appearance".

Following Barbour's (1998: 194) discussion, it is interesting to note that we as researchers are "unlikely to devote as much time or energy to 'sprucing up' quotes from our respondents as we do to perfecting our own prose". That is, in our published texts "we strive for cogent arguments and elegant structure; however, by contrast, we generally take pride in leaving the utterances of our respondents untouched, quoting them verbatim, frozen forever in the inarticulacy brought about by our imperfect questions and need for on-the-spot answers". As a result of such attempts to make the voice of "the other" heard by quoting directly, "we may in fact open ourselves to more criticism than when we embed what particular respondents tell us in generalities" (Brettell in Barbour 1998: 194).

There is no easy answer to dilemmas such as these. In this study this was definitely true. When reading the written version of my interviews with the participants, I have the feeling that they somehow seem halted, drifting even, with tangents and interruptions, with floods of words and sudden silences. The flow of the interviews – once captured on paper – seem awkward, even clumsy at times. Yet this has to be understood as a result of the participants' state of health at the time of the interviews, combined with the experience that they were trying

to describe. Participants were severely ill, some more so than others. This meant that their energies – especially their mental energy – were not constant throughout our conversations. Because of the illness – and the fatigue brought on by the interview itself – participants often lost track of their thoughts, even lost words. And once word and thoughts were recalled, instances forming part of an earlier part of the conversation were often interjected again – before floating off again into the fogginess that was their memory. Also, participants were trying to put into words an experience that eluded easy description. In some cases, participants had rarely thought about it in any depth and now took the time to do so in the interview. Hence, as ideas emerged, these were shared, not necessarily in any coherent order, but rather as they explored and uncovered their own experiences in and through our relationship. While this was exactly the purpose of the interview and of the research itself, it did not make for easy reading once transcribed.

Faced by the "awkwardness" of interviews translated into static text, I needed to establish the extent to which I was willing to change – or edit – participants' quotations for presentation as part of my story. While in a small nagging way I was afraid that the outcome of our conversations could lead readers to doubt the integrity of the research process, or worse yet of the participants, I could not bring myself to completely "edit out" the pauses or even the incoherency. For me it was not only part of the research experience – it was part of the illness experience. It was not a mere hindrance – it was data.

Regardless of the extent of the editing undertaken, researchers typically use participants' narratives to make a specific point (Barbour 1998: 195). This may be done by using their stories in a relatively straightforward way to describe their experience. However, it may also involve a search for significance in the seemingly unproblematic, imputing meaning to an experience as *an example* of a phenomenon in which we are interested. We should however, as Barbour (1998: 195) cautions, be wary of the impact that this approach might have. The participants may not necessarily receive it kindly when their experiences are treated not simply as interesting in their own right, but as examples of something else. They may be offended or feel that "we have breached the contract they believe us to have made with them whereby we have promised to "tell their story"; for now, what we are telling is our *own* story". The implication of this is harsh: for regardless of how much we seek to involve our participants, when we use their experiences to make statements about matters of our own (academic) interest, we ultimately subordinate them to "the uses of the discipline" (Strathern in Barbour 1998: 195).

Thus, for me as for other researchers such as Potter (1996: 94), the production of the final research text was very much like story telling. In other words, I made use of those procedures, so extensively refined in the art of story telling, to paint a scene to make it seem vivid and alive, to talk of a participant as though I have known her for a lifetime, to explore emotions in a way that makes them palpable, even tangible, to the reader. In doing so, I heavily depended on the use of participant statements. And while persistently seeking to do justice to the social world under study, my story was inevitably limited. As the storyteller (with an academic) purpose), I was necessarily selective, emphasising certain details or themes at the expense of others (Barbour & Huby 1998: 12). In other words, I selected for interpretation and presentation a particular range of participant statements while ignoring or backgrounding others. As a result only a part of participants' experiences became "constituted" through my description, while another part was (almost inadvertently) "avoided".

Pawluch (in Potter 1996: 184) refers to this practice as "ontological gerrymandering". Potter (1996: 184-187) explains that, given the infinite number of dimensions comprised within the social reality investigated, any single production would inevitably fall short of including it all. This practice clearly introduces the possibility of producing a description that may differ – in vast degree – from another description concerned with the very same phenomena in. In fact, highly contrasting "versions" of the "same thing" could so be produced without ever reverting to inaccuracy, falsehood or active confabulation. In this sense, then, "ontological gerrymandering" – as the way in which the boundaries of a story is drawn – becomes one of the most powerful devices through which a researcher can (and in this case did) manage the description produced.

Categorising experiences – and people

When observations – any observation – enter the currency of science, they do so in terms of utterances or some form of written discourse. Potter (1996: 167-177) points out that this always – even in its simplest form – involves some form of categorisation. It is therefore not just a matter of seeing; it is seeing it *as something*. By implication, then, categorisation can never be understood as a rather banal naming process through which the right word is assigned to the thing that shows the appropriate properties (as though the word simply *mirrors* the thing!). On the contrary, it is through categorisation that the specific sense, the meaning and qualities, of something is *constructed*.

Thus, the categories through which I had chosen to disclose my story can never be regarded as a neutral or abstract set of descriptive pigeon-holes. Throughout the study, I chose to avoid imposing excessive theoretical meanings onto the story told by rendering the description as far as possible in the terms used by the participants themselves. Although I did not go out of my way to avoid the more abstract language so common to the social sciences, I did find that descriptive terms were often most "experience-near" when they were based on what Pollio et al. (1907: 49) call "body words", that is, terms that relate to the very corporeality of the human experiences under study. Still, despite this approach, the categories through which my description was produced undeniably both reflected and interacted with a broader (theoretical and material) context (cf. Potter 1996: 218). This implies that the repercussions of the chosen descriptive categories may reach far beyond the immediate written research text. It may indeed, as Hacking (1999: 31) suggests, touch the very people and the experiences it seeks to describe.

Hacking (1999: 31) points to a number of repercussions that may follow from categorising experiences – and people – in a particular way. Hacking believes that "ways of classifying human beings interact with the human beings who are classified". There may be a number of reasons for this. People think of themselves "as of a kind", rejecting certain classifications while accepting others. In addition, all our acts are "under descriptions, and the acts that are open to us, depend, in a purely formal way, on the descriptions available to us". This means that the courses of action we choose, and indeed our ways of being, are by no means independent of the available descriptions under which we act. Moreover, "classifications do not exist only in the empty space of language, but in institutions, practices, material interactions with things and other people". In other words, the ME sufferer and her experiences – as constructed in my description – is not only "a kind of" person. She is also a human being, a living entity, who is likely to *interact*, to a greater or lesser extent, with the categories (or classifications) constructed around her and her experience.

Hacking (1999: 31) maintains that such interactions "do not just happen". Being such self-aware creatures, people are aware of what is said about them, thought about them, done to them. They think about and conceptualise themselves. So, an ME sufferer may learn through my construction that she is a certain kind of person – and act accordingly. That is, they may become not only people who suffer from a specific illness, but, in their own self-consciousness, ME sufferers as I have constructed them. They may "make tacit or even explicit choices, adapt or adopt ways of living" so as to fit into or get way from the very

classification that may be applied (have been applied) to them. These very choices, adaptations or adoption have consequences for the very group, "for the kind of people that is invoked". The result may be "particularly strong interactions". What was known about people of a kind may become false because people of that kind may have changed because of what they believe about themselves, or because of how they have been treated or classified. Hacking (1999: 34) calls this phenomenon "the looping effect of human kinds".

Looping effects are, as Hacking (1999: 34) notes, everywhere: "Think what the category of genius did to those Romantics who saw themselves as geniuses, and what their behavior did in turn to the category of genius itself. Think about the transformations effected by the notions of fat, overweight, anorexic". Now think about the construction presented in Part IV and how this might affect the ME sufferer and her experience of illness. Like Hacking (1999: 32), I do not wish to overemphasise the (self-)awareness of an individual. The more important point rather lies in the observation that the categorisations of the social sciences – of this study – are (intentionally or unintentionally) *interactive*. An awareness of this interaction should (and did) sensitise the researcher throughout the construction of a story about the human reality that was studied.

Here my concern was specifically with those classifications that, when known by people or by those around them, and especially when put to work in institutions, are likely to change the ways in which individuals experience themselves – and may even lead people to evolve their feelings and behaviour in part because they are so classified. In other words, I was attentive to the ways in which a classification and the individuals so classified may interact, with the ways in which individuals may become self-aware of being of (classified as) a particular kind, even if only because they are treated as being of that kind, and so come to experience themselves in that way.

Recognising the possibility of such dynamic interaction, Hacking (1999: 162) raises a pertinent concern about the ways in which individuals classified in a particular way must now deal with the difficult question of personal reality. For instance, what would happen to the woman who now comes to see herself as an ME sufferer? In the case of a woman who has been aware for some time that she was suffering from some or other disease, labelled by whatever name, her consciousness has simply been raised. However, where this applies to a woman who was used to ascribing her "symptoms" to work or stress or other circumstances, consciousness has been raised *and* changed. I am here referring to a new world in which a person gains knowledge she

did not have before. She now sees herself as an ME sufferer, because she has a new concept in terms of which to understand herself and her experiences. This scenario emphasises that, in "worlds... constituted by kinds" (Hacking 1999: 162), the experience of ME – as presented in my description – is now a new "kind" that may change people, change their very sense of who they are and what their future might hold.

This effect might not only hold specific (if unintentional) consequences for the individuals involved in and touched by the story I present, but also for the story itself. What my story describes may in effect be (become) a moving target exactly because of the looping effect where responsive, self-aware human beings are involved. That is, my story about the illness experiences of ME sufferers may become known to the people classified, change the ways these individuals behave, and loop back to force changes in the classifications – and the story – about them (cf. Hacking 1999: 108-109). Because the targets of the social sciences are on the move, my story may (almost inevitably) end up having a rather short-lived spell on centre stage.

This recognition points to the contingent nature of classifications. Take ME, variously described as the Icelandic Disease, Tapani Flu, the Royal Free Disease, Epidemic Neuromyesthena, the Chronic Epstein Barr Virus, Post Viral Fatigue Syndrome, Chronic Fatigue and Immune Dysfunction Syndrome (CFIDS), Myalgic Encephalomyelitis (ME), Chronic Fatigue Syndrome (CFS), or even simply "yuppie flu" (cf. Part I). Each of these classifications had a moment of glory. Each one has been associated with a regimen of treatment and a system of exclusion or inclusion. And most of them were thought of as classifications that improved the previous ones. These labels surely affected (or interacted with) the experience both of those so classified and of their families, friends and communities.

At the time a particular classification was in use, it seemed a perfectly natural way to classify people by using a particular combination of signs and symptoms. Yet when we review the parade of ungainly labels, we quickly realise that these classifications are highly uncertain. Each reflects the medical and social attitude of the epoch. And each changed – not necessarily because a better way of classification became available – but perhaps exactly because looping effects demanded re-classification (cf. Hacking 1999: 108-114).

In short, in the production of a description, researchers use categories to classify and describe the experiences being studied. Yet these categories are not inevitable. Like the labels used to

classify those suffering from a specific set of symptoms, these categories are always constructed in a specific period and for a specific purpose. And they could have been different.

Constructing a possible world

Blum (1970: 304-305), referring to the work of Austin (1965), offers substantial insight by describing the conceptualisation of a researcher's story (or "theory") as "a performative", that is, as doing an activity. This means that the story I had told was not constructed for the sake of description alone. It was constructed to perform.

Very much akin to Blum's conception, Potter (1996: 47) too draws attention to the fact that "descriptions are not just *about* something but they are also *doing* something". This means that my description was not only *representing* some facet of the social world and, hence, cannot now simply be treated as some disembodied abstract representation of the social world or of some part of it. No, my description was rather *involved* in the events of the social world it was trying to describe. My description was a "constitutive" part of these events. That is, the sense or the meaning of the events was, at least in part, *constituted by* my description. It is in this sense then that, far from simply representing, my story was performing.

Once we accept the view that a description not only describes but also actively constructs, it makes sense to ask: Of what events or actions is a description part? What is it doing? What activity is being achieved through it? What is it constructing? Is it simply describing? Is it reporting "the facts"? Is it making predictions? Is it instructing? Is it informing? Is it warning? Blum (1970: 304-305) says that a researcher's description does none of these.

Instead, Blum (1970: 313) thinks, a researcher's story should be understood as a method for creating an environment, a possible world. That is, the researcher's story is a "method for transforming an object into a horizon of possibility and this into one possible possibility". The possible possibility – "the possible society" – is what the social reality under investigation means to and for the researcher. In accordance with this view, my description of the human experiences of Others can then be seen as the construction of a "possible society" in a mould that was meaningful to me.

Blum (1970: 313) goes still further and explains that the "possible society" produced by the researcher can be (should be?) regarded as "the theorist's methods for reforming his knowledge of society. Since the theorist is engaged in re-forming his knowledge of society, he can be seen as re-forming *his knowledge*. One who is re-forming his knowledge is re-forming his self". In other words, in creating and re-creating knowledge of society, I was presenting a possible way of seeing society in a meaningful way. And I was doing so out of my own life, out of my own history and biography. In this sense, then, my story had become – in terms of what it had accomplished – an expression of self, even a re-formulation of self. My story had (re-)constructed me.

Thus, far from a passive representation of the social reality in question, my story constituted a dynamic performance. It was a performance that actively constructed the very world it was attempting to describe. It was a performance that constructed how this world had meaning for its producer. It was a performance that constructed me.

Constructing a possible world – with a purpose

Following from Blum's discussion, it is clear that my description is not only a (second-order) construction, created upon the constructs of actors in the social setting under investigation. It is also *constructive*. That is, it is actively constructing a particular version of the social reality under study (as one "possible society"). The fact that I present this version – and not any other – not only testifies to the fact that the story that I tell follows directly from my own subjectivity as Blum's conception suggests. Very importantly, it also hints at a purpose – an objective - that the researcher wishes to achieve by presenting this particular construction. For Hacking (1999: 20), this makes my description *intentionally* constructive.

According to Hacking (1999: 20) a researcher may achieve a number of different purposes when developing a particular construction of the social reality under study. A researcher may wish to expose particular truth claims (in this case about the illness experience of ME sufferers) as not necessarily (as is commonly assumed) inevitable. A researcher may go further, showing that these claims are detrimental and should hence be modified or changed in some way. One way of achieving this objective is by what Mannheim (in Hacking 1999: 20) calls "the unmasking turn of mind". This approach does not seek to refute ideas, but to undermine them by exposing the function they serve. The notion is that once one sees the

"extra-theoretical function" of an idea, it will lose its "practical effectiveness". That is, the researcher unmasks an idea not so much to "disintegrate" it as to strip it of a false appeal or authority. Hacking (1999: 20) labels this approach as "unmasking constructionism". As an "unmasker" in this study I have, in presenting a (alternative) "possible society", endeavoured to expose the ideologies that underlie *the (public) idea of* ME and the suffering it causes and to show what extra-theoretical functions and interests these ideologies reflect and serve.

"Unmasking", as Hacking (1999: 53) notes, has an overtone of "exposing something that was deliberately covered, in order to conceal its true nature". The "unmasking turn of mind", Mannheim wrote (in Hacking 1999: 53-54), is:

> "a turn of mind which does not seek to refute, negate or call in doubt certain ideas, but rather to *disintegrate* them... We must pay attention, at this point, to the phemenological distinction between 'denying the truth' of an idea, and 'determining the function' it exercises. In denying the truth of an idea, I still presuppose it as 'thesis' and thus put myself upon the same theoretical (and nothing but theoretical) basis as the one on which the idea is constituted. In casting doubt upon the 'idea', I still think within the same categorical pattern as the one in which it has its being. But when I do not even raise the question (or at least when I do not make this question the burden of my argument) whether what the idea asserts is true, but consider it merely in terms of the *extra-theoretical functions* it serves, then, and only then, do I achieve an "unmasking" which in fact represents no theoretical refutation but the destruction of the practical effectiveness of these ideas" (Mannheim's emphasis).

Mannheim reveals that intentionally constructive descriptions often tend to be concerned with undermining the authority of knowledge claims and specific categorisations exposing the practical (and detrimental) function they serves. In this study, I sought to achieve such an unmasking by, for instance, showing that society's particular conception of ME provides it with a way of distancing itself from those who suffer from it, thereby creating a secure sense of being outside its reach. This conception also, very importantly, leaves intact (and unchallenged) society's inability to deal with the unknown and the unpredictable. By revealing these underlying functions, the description constructed in this text hopes to unmask (if not wholly undermine) the authority associated with many of society's knowledge claims about ME and ME sufferers.

The intentionally constructive nature of the research description presented here also speaks of a concern about power, often siding with the sufferers as those without or at least with very

little power. This appears to confirm Hacking's (1999: 58) observation that unmasking social construction is often primarily concerned with questions of power and control. The very point of unmasking is, after all, to "liberate the oppressed, to show how categories of knowledge are used in power relationships". While this appears reminiscent of feminist standpoint theory (discussed in Chapter 5), it differs sharply from this approach by taking for granted that power is not simply exercised from above (or in feminist terms, from the surface layer). Seemingly oppressed groupings (even ME sufferers) also participate and even assist in the power structure (Hacking 1999: 58). And perhaps, Hacking speculates, they do so exactly by owning the very categories that are applied to them.

Thus, a description produced in written research findings not only serves to construct a particular version of the social world being studied, but also does so with a particular purpose. That is, it is marked by an objective that the researcher wishes to achieve by presenting *this* particular construction. Given another objective the intentionally constructive nature of the description might change – leading to a wholly different description of the same social world.

Escaping the take-over

As I was writing my story (and, in the process, constructing the world and my self), I was, as Potter (1996: 90) rightly suggests, drawing on and influenced by several different "primary narratives" or what Clarke (1996: 34) calls "meta-paradigms" or "Great Stories". In my story these meta-narratives, in particular, included the belief in the Power of Knowledge, the belief in Science, the belief in Progress and Development, the belief in the Perfectibility of Humanity, the belief in Healing, the belief in the Transcendence of History through Perseverance, even the legitimating belief in Social Research itself. These are the only ones that I was more or less aware of. There could have been many more meta-narratives contributing surreptitiously to my way of thinking... and writing.

Yet, I was not only drawing on these meta-narratives, I was also resisting their temptations. Why temptations? Because, as Clarke (1996: 34) explains, every meta-narrative represents the "last court of appeal" that pronounces on what is legitimate or illegitimate, on what is seen and not seen, on what counts as truth or what does not. Every meta-narrative claims that it is in itself absolute and certainly not in need of any further justification. As a result, every meta-narrative risks taking over the description (my story) and turning it into One True Story – a

version of itself – taking on "the mantle of timeless and unimpeachable fact" (Potter 1996: 90). This I certainly did not want. Not only did I reject the subversive domination of any one meta-narrative in my story; I indeed rejected the very idea that there should even be such self-authenticating schemes of thought undermining researchers' descriptions, let alone mine.

Still, even though I did not want meta-narratives meddling in my story, I could not deny their presence and influence in my study and hence could not, in the process of writing, completely hide their influence. I could merely accept the tensions they had created and attempt to make these known as I went along, telling my story – and not turning it into The Story.

My chosen approach bears close resemblance to Potter's (1996: 93) discussion of the work of Hutcheon (1989) on the "double property" of "both telling a story and undermining the basis of what is told". Hutcheon (in Potter 1996: 93) explains that "it is rather like saying something whilst at the same time putting inverted commas around what is being said. The effect is to highlight, or 'highlight', or to subvert, or 'subvert', and the mode is therefore a 'knowing' and an ironic – or even 'ironic' one". The advantage I gained in making this "double property" mine was that I could at once both disclose *and* question the ways in which I made sense of the social world being studied.

Thus, knowingly and unknowingly, I was confronted by meta-narratives seeking not only to influence but even to co-opt my story into their own versions of "the truth". While I resisted, even rejected, these attempts, I could never deny their influence. What I could do was to expose the strain induced by these meta-narratives by laying open to scrutiny and question the very basis of my description. However, in doing so, I had exposed my story; I had made it vulnerable to its own demise.

Conclusion

"I am trying to find ways to communicate what you know and have experienced so that others may understand" (Barbour 1998: 184).

At first glance, this seems a relatively straightforward and suitably humble explanation of the research enterprise. The simplicity and sincerity of the language, however, belie the enormity and complexity of the task involved. The "knowledge" that I had derived from this study is

the result of a process of social construction in which I, the researcher, played an active role. The *sharing* of such "knowledge" is also a social act. This aspect of the research endeavour, as the question of representation and presentation, has not, however, been subjected to the same amount of critically reflexive examination as has, for instance, the interviewing process. Indeed, as students in qualitative research, we are trained to observe, listen, question and participate. Yet, rarely are we trained to conceptualise the writing process – the process of producing a description – as more than simply "writing up" the research (Barbour 1998: 184).

In qualitative research the act of writing is certainly not a mechanistic exercise of simply "translating" the actual research (a multifaceted experience in time) into writing. It is rather, as this chapter has shown, a process (a method) of discovery in which the descriptions that we researchers produce are not only the products of the research process, but are indeed part of the research process itself (Barbour 1998: 184). As the research develops, and we explore new avenues and identify new findings, so too does our description develop. And by writing it in a particular way, it in turn makes possible the discovery of other aspects of the social world under study. In this way, our descriptions – our stories – become "a way of 'knowing' – a method of discovery and analysis" throughout the research endeavour (Richardson in Barbour 1998: 184).

The unique contribution of the individual researcher in the production of a research description cannot be denied. Unlike a truly disinterested observer, I was personally involved throughout the production of this description. My unique perspective and frame of relevance determined the areas on which I focused and the meanings I chose to explore and represent. As such, my description was inevitably limited. This recognition demanded an analytical engagement with the assumptions and conventions that structure my written work, as well as with the implications and repercussion of this work outside the immediate text. Throughout, this practice of critical reflection afforded valuable insights into the social and political processes through which the final product of research was constructed.

The recognition of my own contribution to the research description furthermore – and almost more importantly – pointed to the fact that the constructions we as researchers produce are dynamic. Not only do they remain open to modification throughout the research process – but also after the process. Our stories remain open to re-interpretation (Huby 1998: 171). Given this, we must realise (and accept) that it will never be possible to say that a researcher has reached "the truth" about something, simply because the truth of one researcher will differ

from the truth of another. That in turn will differ from the participant's experience and the interpretation that the reader attaches to the account (Stark 1998: 212). This myriad of possible interpretations and descriptions permitted by the social world being studied should however not discourage us - it should merely make and keep us aware of the status of our own description, as merely "*one* version of 'what went on here'" (Stark 1998: 212).

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Summary

The question can – and has been – raised regarding the actual truth-value of the story produced through this study. Is this story merely the coincidental outcome of an encounter between one particular researcher and a set of willing participants? Or is it the product of more than pure coincidence? Can my story be regarded as a truthful construction? Can it said to be true?

By now it is clear that there exists an objectivist way of answering any question concerning the truth-value of my story. Schutz (1967: 4) captures the essence of this approach when he states that "to see the world of social facts with an unbiased eye, to classify these facts under concepts in an honest and logical way... this must be the guiding aim of every piece of social research worthy of the name of science". Accordingly, he defines the task of social science as "the simple and accurate description of life in society". Thus, for my story to be regarded as "true", as "worthy of the name of science", it must correspond with a simply and accurate description of the social facts of the reality being studied as discerned through my unbiased eye.

While I certainly share a commitment to the development of an understanding of the social world as experienced by the human beings who live in it, I do not agree with the objectivist way of realising this commitment. I cannot concede that the telling of a truth is simply a matter of "accurate" description, of simply reflecting through the right choice of wording and phrasing the "reality" as it "really" is. Taken to its logical conclusion, this would after all imply that the better our choice of words and phrases, the closer our description would be to "the truth". Yet, like Kuhn (in Hacking 1999: 90), I simply find it difficult to imagine "what the phrase 'closer to the truth' can mean". For me, all social science theory – my story included – does not represent the "closest approximation to the truth", let alone a direct disclosure of it. This would after all presume the existence of an absolute point to which all theory could be compared – a presumption I have repeatedly rejected. For me, all social science theory should rather be regarded as a human construction.

The last emphasis serves to highlight the contribution of the researcher to theory presented. Recognising the "passionate contribution of the person knowing what is known" (Polanyi in Moustakas 1981: 211) in no way implies that I contemplated my own navel. Rather, through

rigor, precision and responsibility, such a recognition alerted me to the fact that whatever understanding I did develop of the Other was the direct result of my Self, *that is, of my own experience of the Other constructed* within my Self *(and not within the Other). In other words, the understanding constructed represented the outcome of my own distinctly human (and, hence, inevitably limited) way of looking and knowing (Maso 1995: 18). Because what was constructed took its form by virtue of my own contribution, by virtue of my Self. I* alone *was responsible for the understanding presented, for the social reality created... for what would be taken as "knowledge". In this sense, my construction of a particular understanding certainly does not reflect some pre-existing truth. It rather more closely represents an act of* bringing a truth into being... through my Self *(cf. Merleau-Ponty 1962: xx).*

So, the truth I constructed does not – and never can – represent the truth. The truth *does not exist. Instead,* my *truth of the participants' experiences is better regarded as* a *story that was deliberately put together (that is, brought into being) for the purpose of the present text. It was designed to convey a certain point, to make a particular argument, to create a particular possible society. With this aim in mind, each and every feature of my story was chosen – for good (though never absolutely compelling) reasons. That is not to say that the story is wrong or inaccurate or even "untrue". For such judgements to be made one would have to presuppose the existence of a definitive participant named Cheryl, a definitive social theory, and a definitive social actuality, to which my story could be compared. And, as we have seen, this is undoubtedly* not *the case. Consequently, this – my truth – is simply a story that works here.*

Thus, I cannot claim that what I have produced is the only story – nor for that matter the best *one. It is, after all, quite conceivable that a different researcher, operating with a different aim in mind, would have made different choices (for equally good reasons) and, hence, would have produced a different story. What is more, my story is open to re-interpretation, to further development, and to the discovery of new meanings. It is, after all, concerned with a dynamic totality – the world of ongoing* human *experience – which it can never fully comprehend but toward which it is continually directed. This acknowledgement firmly places my story in the realm of* human *practice where absolute certainty is neither a required nor even an attainable outcome. It is an acknowledgement that clearly declares that no matter how fine-spun, dazzling and iridescent my story, I find myself in a human world to which I pay the substantial tribute of involuntary recognition. It is the very ground beneath my feet: I cannot so much*

understand it (let alone understand it any better) without depending upon its aid (Fullerton 1912: 3).

Given this, the truth-value of my story can no longer be determined by asking, "how close does it get to the *truth?" It no longer makes sense to ask, "how can I be certain that this story describes the social reality as it* really *is?" Instead, the more pertinent question now is, "Is there convincing evidence for believing that the story told indeed affords insight into the world of the participants?" (cf. Pollio et al. 1997: 53). This question suggests that an evaluation of the evidential support of the story told presents an appropriate way of determining its truth.*

As we already saw, one way of evaluating the evidential support of a story is through recapitulating all that was done in order to construct the particular tale. To this end, I rendered the procedural structure of the present study open to scrutiny. I freed my way of knowing, as it were, the very grounds of all my knowledge. This "freeing" was not only concerned with the rigour and appropriateness of the methods employed, but also very much with my own contribution. In this way, those areas of research and truth construction, marked by a fusion between my Self and the social reality under study, were exposed. In the process it was possible to reveal that the methods of this study were employed with a conscious and deliberate awareness of their implications for and appropriateness to the understanding claimed.

Still, to show that I have paid my dues to the scientific practice of my discipline is not enough. *It offers only part of the evidential support that determines the value of my story...*

What supplements method, or perhaps even surpasses it, is insight. *The important question here is whether the evidential support contained within my story allows the reality under study to be regarded in a different way, a new way? Does it provide an alternative way of knowing? Does it broaden our understanding? Moreover, does it offer a possibility of improving this reality? This, the offering of new perspectives, of new ways of looking, of new possibilities, represents the very purpose of all social research (Maso 1995: 19).*

For a story – my story – to be judged as a truth (or at the very least as truthful) requires full marks on both *accounts: method and insight. Neither functions separately. Indeed, there can be no "truth" without either one or the other as there is a strong reciprocal relation between the two: the more adequate the methodology, the more insightful the results are likely to be.*

Conversely, if a study generates an insightful story, the more disposed the reader will be to judge the method as adequate. What I propose here, then, is that concerns of both method and insight are relevant to the evidential support and, hence, the truthfulness of a story. Well-executed procedures that do not generate meaningful results are technique without soul. Brilliant interpretation may have value, but one needs to be convinced of the evidence serving as the foundation of such findings in lived experience. Only when both *criteria are met does a story attain the rigour and insight that it aspires to attain... and that are likely to convince others of its significance (cf. Pollio et al. 1995: 55). Stated differently, only to the extent that the standards of both method and insight have been satisfactorily accomplished is it possible for my story to carry any "truth"... for my "possible society" to have any right to existence.*

What, then, can be said about my story?

While my story is not the truth, *it is without doubt* truthful. *It describes a world of human experience in a way that is methodologically sound as well as conceptually attuned to the utter complexity of the reality it dealt with. What is more, it describes this reality in such a way that it permits the development of new insight, accompanied by the added promise of improvement. So my story has constructed* a truthful claim *about one world of human experience in all its fullness.*

Moreover, the value of my story is not only confined to the truth it holds. Its potential indeed reaches further than truth... and touches on hope. Without fail, my story brings back the full humanity *of the social researcher to the field of social research and, correspondingly, reinstates social science as undeniably part of the distinctly* human *world of social life. My story inspires hope for the pursuit of an understanding of the human world in a humanely responsible way so that social research will not only to be a fully* human *enterprise, but indeed a* humane *one too.*

To the extent that you, the reader, find this to be the case, it is possible for you to accept my story as the product of an endeavour that ceaselessly aspired to do justice to the human reality in question.

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Chapter 21
Conclusion

Plummer (in Heaphy 1998: 23) observes that "the ceaseless nature of story telling in all its forms in all societies has come to be increasingly recognised... Society itself may be seen as a textured but seamless web of stories, emerging everywhere through interaction: holding people together, pulling people apart, making societies work".

Because of its significant role in constituting the very fabric of society, the value of the story and its telling have also been recognised in the world of social research. Here, the story is recognised as one of the central routes we as social researchers have "into the continuing quest for understanding human meaning" (Plummer in Heaphy 1998: 23).

This was particularly true in this study. It was indeed all about stories. Throughout, the research focus was directed at the stories that participants told of the personal meaning of having ME. And it was about my story – the one burgeoning from the participants' stories, yet never telling quite the same story as theirs. The entire text indeed represents a story – a traveller's tale – about a research journey undertaken in a world of illness experience.

So, as my research journey concludes, it is perhaps the most appropriate time to reflect upon this story and its implications for the world of illness and the world of social research.

The story about having ME

Against the background of Part I, Part IV of this study was dedicated to the discoveries made in pursuit of an answer to one question: What is the subjective illness experience of those who suffer from ME? Each discovery was known and knowable only through the stories recounted by those who endure the suffering of ME.

Their stories first and foremost told of the physical reality of ME. This reality is marked by tremendous change encompassing virtually every level of physical functioning. On the reverse side lies the human reality of ME. Each participant's story revealed that the human reality – the experiential, subjective experience of extensive physical disorder – involves the person as a

whole. The person's interaction with and within the social world, as well as the person's relationship with the Self, braves change, disruption and turbulence of a profound and encompassing nature that leaves no dimension of existence untouched. This then represents the double jeopardy of ME: an illness so intensely severe and disruptive that it not only impairs the physical being but intrusively claws deeply into the human actuality as well. It is not simply an impairment of the body. It invades the total person.

This double jeopardy is exacerbated by the influence of the demon of ignorance. This demon fills the sufferer's experience of bodily disorder with confusion in the face of a bewildering and largely inexplicable array of signs and symptoms. It turns the physical being into an unreliable adversary. Within the world of social interaction, ignorance also wreaks havoc. Because of ignorance, ME has become widely misunderstood and mishandled in virtually each and every circle of social interaction. Because of ignorance, the social world not only lacks any true understanding of ME, it has also actively distanced itself from the ill. This has left the ill misunderstood, and wholly deserted in their suffering. In addition, the demon of ignorance has invaded the ill person's experience of the Self. When the personal experience of Self appears to be so foreign to what was once known and secure, the ill person not only experiences hurt-filled loss and surrender, but also begins to doubt and fear the Self. There is conflict with the Self, within the Self.

Thus, based on the stories related by those who suffer from ME, their subjective experience of illness was one characterised by physical disorder so extensive and severe that it spilled over into the disruption of their human actuality. By so profoundly altering the previously taken-for-granted, in ways that seemingly defied explanation, the illness experience not only left the participants feeling limited and compromised, but also very much stigmatised and marginalized. For participants, then, the threat posed by ME to the body and the Self was not confined to the disease alone, but also reached into an existential awareness of disruption, loss, and fear. Perhaps, in the end, this was the more direct threat – the one that stemmed from culturally informed understandings – or stories – of what it means to be "normal", autonomous, and in control – and the poignant realisation of no longer being able to meet the standards and expectations they imply.

This recognition clearly suggests that the ME sufferer's response to and experience of illness are formed by more than the purely physical disorder imposed by the specific disease. Rather, their attempt to make sense of – and give voice to – their illness experience is also very much

formed by the broader social and cultural stories that permeate their time. After all, in sustaining and revising their sense of Self in the face of illness, the ME sufferers in this study were faced with a multiplicity of stories regarding the "true" meaning of their symptoms. These included accounts from doctors, psychiatrists, councillors, as well as accounts provided by those who either suffer from a (seemingly) similar condition or profess to know someone who does. However, Heaphy (1998: 23) reminds us that our thinking is typically dominated by medical and scientific narratives. These then represent the master narratives or stories through which ME has been given meaning – to the ME sufferer and in society.

Such "medico-scientific discourses and narratives on the meaning of illness and disease are", Heaphy (1998: 23) argues, "far from neutral accounts of the 'truth'. Rather, they are bound up with strategies of power, and have a crucial role to play in a disciplinary society". To explain this role, Heaphy refers to theorists such as Foucault (1979) who have characterised power as it is productive, and partly operates in a disciplinary society through an incitement to self-regulation. According to this view, power also operates in line with binary divisions between "mad/sane", "normal/abnormal" and "healthy/sick". Following this, medico-scientific discourses around ME play a crucial role in investing people with ME with a distinct sense of place, function and attribution, and in positioning them within these binary oppositions. Thus, just as ME can produce a physical reality marked by chronicity and disability, the social experience of suffering from ME can produce self-knowledge of one's "difference", "abnormality" and "otherness". In this way, it becomes possible to understand the self-knowledge of ME sufferers as being wholly bound up with medical and scientific constructions of the nature of this syndrome – and with the power relations which these constructions are both based on and give effect to.

Participants' stories furthermore revealed that the dominant ME narratives produced by the medical and scientific worlds were closely interwoven with broader social and cultural accounts of what it means to be rational, sane and normal. In a Western cultural setting specifically, a unitary body and autonomy combined with adequate involvement in culturally marked social relationships, are profoundly bound up with notions of "Self" and what it is to have a "normal life" (Monks 1995: 471). When sufferers divert from the norm, from what is accepted, they "stand out". When it then becomes apparent that the reason for this deviation is an illness that seems completely impervious to the powers of modern medicine, society somehow becomes vulnerable. The illness then becomes a symbolic marker on which society hangs some of its most important fears, hopes, prejudices and beliefs about itself and the world

it lives in. The symbolic status of the illness also becomes a reason enough to blame the "victims", to stigmatise them, and to shun them (cf. Barbour & Huby 1998: 6).

Thus, the stories and constructions that pervade the medical and scientific world, as well as society itself, label the ME sufferer as deviant and identifies her with a medical enigma which borders on evil itself. In the face of these stories of what they ought to be – and what they are obviously not – participants in this study needed to achieve a "reconstruction of Self" (Conrad in Monks 1995: 471). They achieved this.

Participants' stories revealed that the very real onslaught of ME on all dimensions of actuality inspired them – perhaps even demanded – to a greater awareness of Self. To become able to live with a changed Self, the participants needed to reflect on the Self and its states, understand the Self and its responses, and appreciate the Self and its interpretations. Such a deeper state of self-awareness made it possible to again believe in the Self and in the reality of their own experiences. In turn, the renewed belief in the Self empowered them to realise that they themselves have the power of choice. Through the power of choice, they regained personal control over their own experience of illness. Thus, while participants could not necessarily change the physical state and course of the illness itself, they could rework their own experience of it.

By structuring the Self in a particular way, the participants in this study no longer needed to feel like powerless victims. Rather, they could firmly return their experience of body, Self and social to the realm of personal control and in this way "generate" a new empowered Self. This understanding hints at the human ability to (re)construct a Self by thinking (and talking) about the Self in a particular way (Kelly & Dickinson 1997: 276). This ability, however, also leads to an uneasy sense of suspicion: could a story about the Self, and told in a particular way, not perhaps be false, or only partly true?

Kelly and Dickinson (1997: 276) recognises this concern, but for them it does not present a serious problem. As the Self, the story produced about the Self is "orderly". And even if this order is only linguistic in so far as it is imposed after the event, it remains important, for it is the order that gives shape and meaning to past life and helps render the unknown future slightly less frightening. It is in the transient moment of now, where past and future is so simultaneously juxtaposed and intertwined, that the Self is experienced and constructed. It is this construction which "sustains the continuities of the Self and also accounts for and

refashions discontinuities of the Self through time" (Kelly & Dickinson 1997: 275). Very importantly, this suggests that the Self is no static entity. It is an (emerging) configuration of personal events into an experienced unity which includes what is, what was and what will be.

What does this mean for this study? The stories on which it is based – the participants' stories about the Self and its experience of ME – were not conceptualised as merely reflecting or describing a world already made. Rather, each participant's story is understood as an active lived process, inseparable from the Self at the moment of telling. The account given of an autobiographical experience is then "not an entity external to the person giving the account"; it "*is* the experience" lived in that moment (Kelly & Dickinson 1997: 254-255, emphasis added).

This understanding of participants' stories – as a lived process – not only informed my evaluation of the data – the stories – with which I worked. It also informed my concept of the very experience under study. In telling their stories, participants moved back and forth, reflecting on the past, anticipating the future. So too in living their lives with ME. Here they also moved back and forth, further and closer to the world created by master narratives and the world of severe illness. Cultural expectations were juxtaposed against patterns of distress. Marginalization was followed by acts of resistance. In this way, a life lived with illness became regarded as "a continually developing trajectory" (Ware 1999: 323). Illness experience could no longer be narrowly defined as subjective feelings of distress related to illness-focused acts. The illness experience of the participants in this study was concerned with far more than acts directed at defining symptoms, attributing cause, seeking help and complying with treatment. For them, illness happened to the whole person.

It is for this reason, and because it seems to reflect human experience more directly, that the continually developing trajectory of a life lived with illness, as a way of thinking about illness experience, merits further exploration in future studies. Such an exploration would not only apply to the area of ME, but is likely to prove equally useful for understanding experience in other types of illnesses that are unquestionably physical but at the same time also highly controversial. In this way, medical sociology will transcend any lingering mechanistic understandings of disease through experience-near analysis that creates a legitimate space for the social and personal dimensions of the illness experience (cf. Kriel 1997: 187).

The story about my story

To a very significant extent much of this text can be read as a travel report about my journey into the ME world of illness experience. It has outlined the route followed through the stages from an original idea to this, the final report. Conversations taking place along the way have been recounted and reflections on the events that were encountered have been provided. And still one question lingers: what can really be said about this text, about my traveller's tale, about my story itself?

Dey's (1993: 242) statement that "our 'facts' are produced through our conceptualisations is very important. Bohm (1983) notes that the root of the word 'fact' is "that which has been made' as in manufacture – our 'facts' therefore depend on how our perceptions are shaped by our thinking". What holds true for "our facts" similarly holds true for the story constructed throughout this text. In other words, this story represents a product that has been "manufactured" or, if you will, a house that has been "built".

A house consists of many bricks put together in a particular way. In the case of this story, the stories constructed by participants through our relationship represent the bricks. These stories were constructed within a particular context (the research relationship) and for a particular purpose (the development of a better understanding of their illness experience).

Does this imply the possibility that constructions of the same experiences made in different conversations bear little – or worse yet, no – resemblance to one another? And what would this mean for the house to be built?

Admittedly, no guarantee exists that a set of different purposes and different contexts will yield similar constructions of experience. After all, Collingwood (in Williams 1989: 270) suggests that what has been constructed by participants – their experiences – is the distinct product of one particular moment in time. That is, "every present has a past of its own, and any imaginative reconstruction of the past aims at reconstructing the past of this present, the present in which the act of imagination is going on as here and now perceived". Thus, the past of illness experiences constructed within our research relationship is the past of that present in which our relationship was situated. What was constructed was constructed from that particular present with its own particular past. This implies that a different present (or context) perhaps ruled by a different purpose, might yield different constructions of the past, that is, of the participants' experiences. In this sense, then, there exists no way for me to present

evidence for or against the proposition that a substantially different construction of participants' experiences (their past) may arise within a different context governed by a different purpose.

Still, like Pollio et al. (1997: 34), I believe there to be an air of intercontextual coherence surrounding the constructions of experience underlying my story.

One basis for the belief in intercontextual coherence of experience is that a person's experiential field is, as suggested earlier, organized rather than chaotic. That is, "in the day-to-day flow of experience, change is experienced against the stability of one's social surroundings, activities, and self-awarenesses. The relative stability of the personal field provides one basis for expecting personal meanings to bear coherent, if not identical, intercontextual relations. While specific meanings may change across contexts, such changes are likely to bear systematic relations that can be understood within a holistic framework" (Pollio et al. 1997: 34). In other words, I have reason to believe that the experiences constructed by participants do not merely represent some volatile or erratic flight of thought. Instead, such constructions are much rather likely to reflect the coherent stability that typifies a participant's field of personal meaning.

A further reason for believing in the intercontextual coherence of experience concerns "the temporal dialectic between a person's history and the present-centred nature of remembering. In the conventional sense, a person remembers something from his/her own personal history even though the act of remembering always occurs in an ongoing, present situation. The meaning of one's past is shaped by the present context, although the past that is remembered is not totally mutable. A person's history has a certain facticity that serves as background for his or her day-to-day functioning. That is, the historical certainty of one's past is seldom questioned: We know the ways in which events of our past relate to the meanings of present dialogue. A dialogic view of remembering does not imply that reflections will necessarily be radically transformed in individual settings so as to be contextually idiosyncratic, although such a state of affairs is not precluded. Rather, the usual situation is that the act of remembering brings about a temporal fusion of the present and past in which a personal historical understanding is revised to accommodate a present perspective, and in which the present perspective is contextualized by one's history" (Pollio et al. 1997: 34). Thus, unlike Collingwood's view, Pollio et al.'s perspective on remembering is that what is remembered in a particular present is neither entirely governed nor wholly transformed by the nature (context

and purpose included) of that present. Instead of such a one-way influence, there is a "dialogic" interplay between present and past when the latter becomes the subject of construction within the former. What is then constructed is not a pure reflection in words of what "really" happened, of some "internal representation" of the past. Rather, as I suggested earlier, what is constructed, for the research and in the research relationship, *is* the experience.

In combination, these two reasons for believing in the intercontextual coherence of experience supports the view that reflections emerging in one conversation - that is, in one research relationship - will not be wholly different from those emerging in another context directed by a different purpose. There may even be no difference at all.

Up to this point I have established that the building material I used – the participants' stories – were produced within a particular context, for a particular purpose. This fact appears to shed some doubt on the "solidity" of the building material. Yet, it does so only if we insist on believing in one true reality to be purely reflected in participants' words. If we instead believe that the experiences constructed in the research relationship are the experiences as lived by participants, then we accept that our building material is the best they can be: the very personal constructions of experience by the participants themselves. And as the participants' field of personal experience is neither chaotic nor completely subject to the present context of remembering, we cannot but have confidence in the highest quality of the bricks I had chosen to use.

However, the quality of the bricks does not necessarily guarantee a well-built house because bricks alone do not simply "make" a house. They have to be put together in a systematic and orderly manner by the builder who follows a design and adds the cement. Similarly, in this study the researcher, I, built a house. It is *my* house.

Much has already been said, in this study and elsewhere (cf. Huby 1998: 164-165), about the way the researcher's Self – as the researching I – shape the research process and its outcome. Warnings have been issued that many researchers have gone too far in this direction and are loosing sight of the research encounter as a social rather than private event. Stated differently, this means that we researchers have started contemplating our own navels and, having been caught up in the intricacies of our own experiences, failed to move on. The danger here is that researchers may, as Potter (1996: 232) puts it, become so "bewitched by reflexivity", so concerned with an exploration of their own navels, that the human world, with all its interests

and problems in need of greater understanding, will simply flitter by them, unnoticed, unchanged, unaccounted for. This is not to deny that the researcher's navel may yield excellent insights towards greater understanding, but it is certainly not where our quest towards such understanding should end.

While acknowledging the possibility of overly enthusiastic reflexivity and the danger it holds, I argue that there are still areas of research practice that can benefit positively from critical reflection. Here I suggest that we must direct our critical gaze to the space that exists between the world under study and the theories – the stories – we develop about it. When we assume such a position, we become able to both comprehend and reveal the mediating practices and processes of science at work within this critical space (Huby 1998: 165).

In this study the practice of critical reflection made it possible to recognise that in building a particular construction – a story – I had to add cement, that is, my own interpretations. Yet, I have to recognise that different (alternative) interpretations were (and still are) possible. The bricks could have been put together in a multitude of different ways; each way leading to new possibilities, each way introducing new potentialities of meaning, each way unfolding a uniquely different construction of the world in question. In fact, there was for me no sure way – and certainly no absolute way – of reaching an understanding of the participants' human experiences. There was only my way, which was pervaded by my own humanness. Indeed, my contribution to the construction of the story about a human world of experience cannot be separated from my subjective experience of the occurrences through which I came to know that world. I cannot but recognise my own human Self – the very presence and influence of the researching I – in every act of knowing.

This recognition was furthermore accompanied by my identifying the conditions which structured my gaze and its *transformations* as time passed. This becomes remarkably clear in the final text. In Part IV, for instance, is part of the work I wrote shortly after completing the interview cycle of my research. The interviews with the participants and the experiences they conveyed were still extremely vivid in my mind. I had had hardly any time to distance my Self from the field. Hence, my interpretation and construction were both enabled and constrained by my own involvement. In contrast, Part V, which was written more recently, shows a far greater distance from the research setting. Emotional responses have become more vague, less explicit. I, the researcher, have become more detached. Yet, through this very detachment I might have, I fear, also lost some of the intensity that made this study such a powerful one.

The significance of this experience lies in highlighting the importance of not leaving critical reflection too late. It should (and can) take place before we distance ourselves completely from the actual research setting, and should continue until the final report has been produced. In this way, the very act of critical reflection can become an analytical tool that informs the study throughout its course.

Critical reflection can still go further… the story that I was able to tell was, after all, framed by more than just the immediate research setting. It was influenced by prevailing concerns that stretch well beyond the immediate research context. This implies that our reflective gaze must extend beyond the research interaction to encompass the wider (and shifting) context in which this encounter takes place (cf. Small 1998: 141).

In this study, extending my gaze beyond the Self and the participant, leads to greater attention to the master narratives that have shaped my participants' stories – and my own. The present construction can after all be seen as an attempt to unmask the present day understandings surrounding the illness experience of ME sufferers. Thus, an awareness of such (mis-) understandings have shaped my own. Furthermore, the construction presented can also be seen as an effort to unmask an ideology of science which I believe is no longer meaningful. It is an ideology that appears, as I have shown, to produce pious reverence for scientific truths about the world that come to us in a neatly pre-packaged structure. Again, my response to this ideology has – very strongly – influenced my own construction.

Thus, the story produced and presented through the present text is undeniably a product of my own doing and reflects a very particular period in time. But does this recognition, this confession of my personal involvement, not cast a murky shadow over the truth-value of my story?

My story, as I have argued throughout, must be regarded (and evaluated) strictly in terms of what it is (or what it at least proposes to be): a story that set out to describe a world of human experience in a sensitive and appropriate way so as to allow new insight and even the hope of improvement. It does not in any manner represent *the* truth about the world in question. It makes no claim to an enduring status of unquestionable truth. It is *a* truth about one world of human experience in all its fullness and complexity. It is a story that works here.

And while this is indeed a story that I have produced through my Self, I see no reason to believe that it should necessarily be regarded as any less "truthful" than a story produced through a different researching I. If I feel brave enough I might even venture so far as to insist that – exactly *because* of my personal involvement *and* my critical awareness of it – my story might just be better.

Moreover, far from questioning its truth-value, a recognition of the undeniable human involvement in the construction of a story about one human world, very importantly, places my research neatly within the realm of *human* practice. Indeed, this is not only where my research belongs, it is also where my science resides... or at least, should reside. For it is in this world, where there is no absolute certainty, where knowledge becomes a fantastic risk. It is in this world where potentialities abound, with the prospect of converting the human practice of social research into a distinctly *humane* one certainly not the least of these.

Still, after arguing so valiantly to establish that my story contained a truth of great potential, I must ask: Could it perhaps have been better in any way?

Perhaps yes... The practice of critical reflection I proposed and employed in this study opened several avenues of investigation that might otherwise have remained closed. It indeed enabled a very particular (and, I hope, compelling) story to be told about a world of lived experience. Yet, this practice – and hence my story as its product – will benefit greatly from sufficient supervision and support structures for individual researchers. In the absence of such structures, the emotional well-being of the individual researcher may be compromised. And while much damage limitation may take place in informal encounters where confessions are exchanged, supported provided and blame apportioned, these sessions rarely go beyond the private and informal. It often seems as if it is only the most secure and arrogant of us who dare treat their own experience as data in public. And even where they do, the balance is not always successfully achieved between intellectualising painful and conflicting experiences on the one hand, and making practical and liveable sense of it all on the other hand.

We must, therefore, rather bring these private deliberations among researchers into the open so that we fully realise the opportunity to enrich both practice and theory through our shared experiences. And we must do so in a way that extends a kind of support that will encourage fellow researchers to take this risk too.

Final words

The products of our science, the theories we produce, the stories we tell are, so to speak, always "made", always under construction. And they always express a particular human understanding, a perspectival insight. To be regarded as valid knowledge claims, these products need not perfectly correspond to some social reality "out there". To assume that they should, would be to conform to what Putman (in Hacking 1999: 101) calls the "common philosophical error" of "supposing that 'reality' must refer to a single super thing". Instead, in evaluating our science and its products we should look at "the ways in which we endlessly renegotiate – and are forced to renegotiate – our notion of reality as our language and our life develops" (Putman in Hacking 1999: 101).

From this, it follows that one of the reasons why we tend to become so confused in debates about whether something is "real" or not is that we fail to attend carefully enough to the language that we use. So, when I say in this study that the illness experience of my participants were "socially constructed" through their stories, and their stories in turn by mine, I do not mean that it does not exist, that it is not "real". Rather, I mean that *the idea of* this illness experience is open to social influence, to the ways in which it is conceived by the participants, by my Self, and by the network of milieus in which we live. That is, it has been "made" or formed within a larger matrix of practices and institutions that surround this particular type of experience (Hacking 1999: 101).

In a similar way, the story presented here should be regarded as "socially constructed". It expresses a particular understanding attained within a particular context – or matrix – of practices and institutions that surround and influence the social research enterprise. Given then a different context and constructor, the stories on which my understanding is based might very well be understood differently, and, in the process, yield new meanings (Pollio et al. 1997: 350). Indeed, the very real possibility that some might question or disagree with my text serves as a strong indication of its potential to be re-constructed, re-worked. And, with each reworking of my understanding, new resources for future renditions are produced (Monks 1995: 454). This too essentially captures the nature of human understanding as "an ongoing dialogue" (Pollio et al. 1997: 350) in which new meanings may always be constructed, and reconstructed.

Such new meanings are exactly what we should be looking for as it is in these meanings that the richness of perspective and interpretation so characteristic of the human world is situated.

Yet, in creating such meanings (and their renditions), we must remain wary of the fact that as we do so, we are creating particular "boundaries" (Hacking 1999: 167). In this study, the meaning-bearing constructions created around one illness not only affect the state of our knowledge about it. It also impacts on the possibilities and opportunities that remain available, on the very nature of the (ideal) world in which we live – and where ME sufferers live. In creating these boundaries of knowledge, we are indeed assuming an immense responsibility for we are creating a possible society that might influence – if not become – our actual society.

This recognition of the responsibility that accompanies the construction of our stories should not, however, overwhelm us into a state of inaction. For if it renders us incapable of saying anything significant for fear of creating a disjointed world, how could we ever justify the right to ask for the stories that make social research possible in the first place? How would I ever be able to justify the stories provided in good faith by the participants in this study? After all, if their experiences were important enough to document initially, they are still important enough to write now. Hence, while appreciating the responsibility that we as researchers carry, I must conclude with Stark (1998: 216) that "it is important to take the risk and say something, rather then err on the side of caution and end up saying nothing".

Writing our stories, then, is a risk we must take.

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Appendix A

Introductory communication with potential participants

[Address]
Stellenbosch
7600

August 1999

Dear [Participant's Name]

Thank you so much for responding to the appeal to participate in this study. I truly do appreciate it – especially as it serves to encourage my belief that with the help from people like you this study will be able to make a difference within the field of ME.

I have, as promised, included a brief outline concerning the motivation and design underlying this study. Ideally, this outline should facilitate your final decision about participation in this study. If you should have any further questions left unanswered by this outline, you are of course more than welcome to contact me at the above stated postal address or at the below stated e-mail address or telephone number.

Also, please find enclosed a letter written by my supervisor, Prof. J. Mouton, indicating the University of Stellenbosch's official endorsement of and support for this study. Set against the background of this letter, I can also assure you that this study will proceed under the guarantee of complete confidentiality. In addition, I would also like to emphasise that it will indeed be possible to accommodate your own unique circumstances in the way in which this study will be conducted.

Once again, thank you for the interest you have shown in my study. I will then be sure to contact you in the very near future to confirm your participation and to possibly make further arrangements in this regard.

Yours truly,

Ansie Carstens

Tel. 021 – 883 4567
E-mail: 12345678@maties.sun.ac.za

THE ME RESEARCH PROJECT

Why a study about ME?

Through this study, I would like to contribute towards a greater understanding of the personal experience of those who suffer from ME (also known as CFS and CFIDS). As such, I will attempt to stimulate the emergence of a more informed social and medical understanding and recognition of ME as a real and extremely disabling disease.

I am aware that some may argue that any public recognition of ME as a real disease is very unlikely without the unambiguous recognition of ME within the medical profession. However, I do believe that a greater social awareness within society as a whole will filter through to the medical establishment where it may trigger greater interest in further research within the field of ME.

Who will qualify as participants for this study?

I have, for various reasons, decided to select only a small number of ME sufferers as participants for my study. Each of these participants must at least fulfil the following four criteria:

Participants must be female.
Participants must be between the ages of 20 and 50.
Participants must reside within the Western Cape region.
Participants must be medically diagnosed as suffering from ME.

As such, those ME sufferers that are finally selected for my study will not only share a similar demographic profile, but will also be representative of the group most targeted by ME.

What will be expected of participants?

Each participant will be expected to grant at least two in-depth interviews during which you will be asked to describe your personal experience of ME. These interviews, which will be conducted under the guarantee of complete confidentiality, may later be supplemented with further discussions during which I will be able to clear up any uncertainty on my side and during which you will have the opportunity to correct any errors concerning quotation or interpretation. In addition, each participant will also be asked to compile a short autobiographical sketch through which I will be able to gain even greater insight into your personal life world.

This structure is, however, very flexible and can be readily adapted to each participant's state of health and well-being. If it would, for instance, better suit you to conduct four shorter interviews instead of two longer ones, then this can be arranged. It is thus important that you should know that the way in which this study is going to be conducted can be readily adapted to your own circumstances.

In light of this flexibility, it is difficult to give an accurate estimation of how much of your time this study will consume. A usual in-depth interview can, in accordance with the degree to which you are willing to participate and share your experiences, last anything from one to two to even four hours. This will completely depend on you and how you feel. Each participant will similarly be able to determine how much time you will invest in the compilation of the autobiographical text.

I can, however, mention that the interviews will commence from mid-August onwards. After the first set of interviews, participants will have roundabout three weeks during which to compose the autobiographical sketch. This will be followed by further interviews. The entire process may, again depending on you, the participant, last between one and two months.

UNIVERSITEIT VAN STELLENBOSCH
UNIVERSITY OF STELLENBOSCH

15 July 1999

TO WHOM IT MAY CONCERN

I hereby confirm that Miss Ansie Carstens is doing research on ME as part of a Masters Degree in Social Science Methods. This is an official research project of the University of Stellenbosch and I would appreciate it if you would give her the necessary co-operation.

Yours faithfully

JOHANN MOUTON (PROFESSOR)
Department of Sociology

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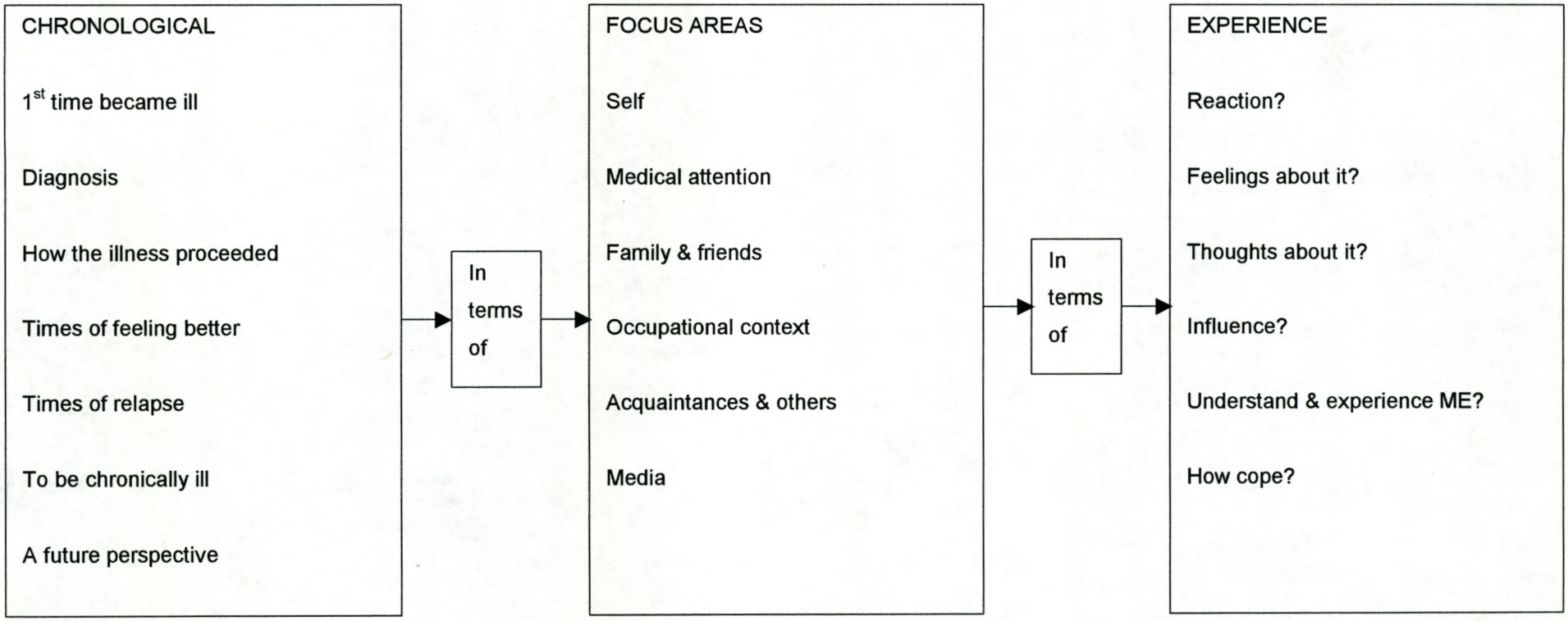
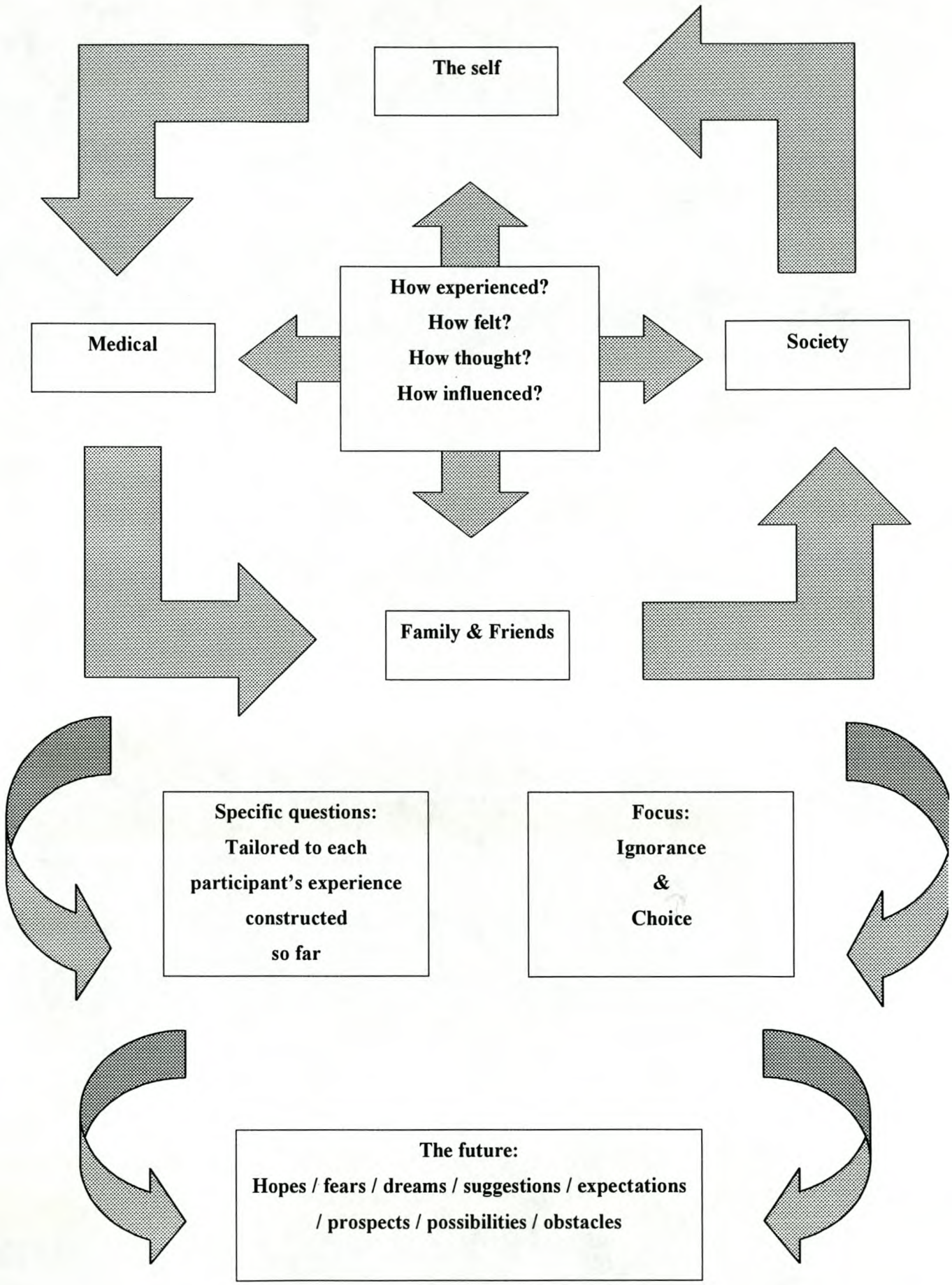
Appendix B

Guide to first interview



Appendix C

Guide to second interview



Appendix D

Approaching the research topic

At the onset of our first interview, I introduced and explained the research topic:

I would like to start by explaining how I hope **our conversation will proceed**...

In our conversation today, I'd like you to tell me **your story about having ME**, to describe to me what it has been like and what it is like to have ME, from the time it first started up to now, how the illness proceeded, how you experienced it, how you've felt and what you've thought about it, and also how you have managed to cope with ME throughout. You can also tell me about other people's reactions (such as family, friends, doctors, co-workers and acquaintances) to ME and to you personally as a ME sufferer and how you have experienced and responded to such reactions.

As this will essentially be **your story about having ME**, about your own experiences of this illness, I'd like to emphasise that our conversation will not assume a simple question-answer format... instead I almost want to say: 'the floor is yours'. This is your opportunity to tell me and perhaps a number of other people what it is like **for you** to have ME, how **you** have experienced this illness as you live with it day after day...

Now, I suspect that the easiest way for you to tell me about your own experiences of ME, to tell me **your story**, may be to **approach it in a more or less chronological way**. You may, for instance, begin by telling me about the very first time when you became aware that something was wrong, then on to when you were diagnosed, how your illness proceeded, and how it is to have ME now, how you experience it, understand it, and cope with it.

I'll appreciate it so much if you could tell me your **story in as much detail as possible and also with the use of very concrete examples wherever possible**... this will help me to make sure that I truly understand what you have in mind and what having ME has been like for you. This will also help me not to confuse your experience of this illness with my own background, with my own set of experiences related to having ME. I do after all want to understand **what ME has been like for you, how you have experienced it**. And as I hope that your story will contain so much detail, I'll use this compact cassette **recorder** to ensure that I don't forget anything you say, your words, your experiences, your examples.

Now, from what I've said and from what I've explained, is there anything that's not clear, do you have **any questions**?

Fine, then, when you are ready, you can start off **by taking me back to the very, very first time when you became aware that something was wrong** in your body, what happened then, what were the circumstances, what did you think and feel, and what did you do... the very first time you became aware that something wasn't right?

Appendix E

Termination of interview process: Asking for impressions

At the end of our last interview, I asked for participants' impressions of the research process:

Now, just before we conclude... I have one last thing to ask...

It would truly mean very much to me if you could **honestly** describe to me your **personal experience** of our interaction throughout the entire research process and then especially within the context of our two interviews.

Was it, for instance, very **difficult for you to talk about** yourself, to share your experiences with me? Did you sometimes struggle to find the words to describe your experiences? Did you at times experience it as uncomfortable or difficult? Were there perhaps any parts that were more difficult than others to share? Were you ever concerned about the issues such as **confidentiality and trust**?

Did our conversations have any **influence** on you outside of the specific interview situation? Did what you said during the interviews or the questions that I asked prompt you to think more about some aspects or perhaps to think differently about others than you had before? Did you perhaps discover something about yourself or about your own situation which you had previously not been so aware off?

Can you think of any **'mistakes'** that were made or any **problems** that might have been avoided? Do you have any **suggestions** through which a study such as this one could be planned and conducted more effectively in the future?

Is there here **anything else** you would like to add or ask?

Appendix F

Introduction to the TSCS

Towards the end of our first interview, I introduced and explained the TSCS:

Just before we conclude for today, I would like you to complete this very short questionnaire – it will not take any longer than about 20 minutes to complete. It is called the **Tennessee Self-Concept Scale** and consists of a number of statements that can **help you to describe yourself and how you feel about yourself**.

This little book contains all the statements. Each statement describes how a person can feel about him- or herself. You can then decide **how accurately each statement describes the way you feel about yourself**. This you can do using the 5-point scale that appears at the top of each page. In other words, if the statement describes your view of yourself perfectly, you can encircle a 5 on the answer sheet, while a 1 will show that you certainly do not think that the particular statement represents the way you feel about yourself. As there are of course no right or wrong answers, please feel free to describe yourself as **honestly** as you can.

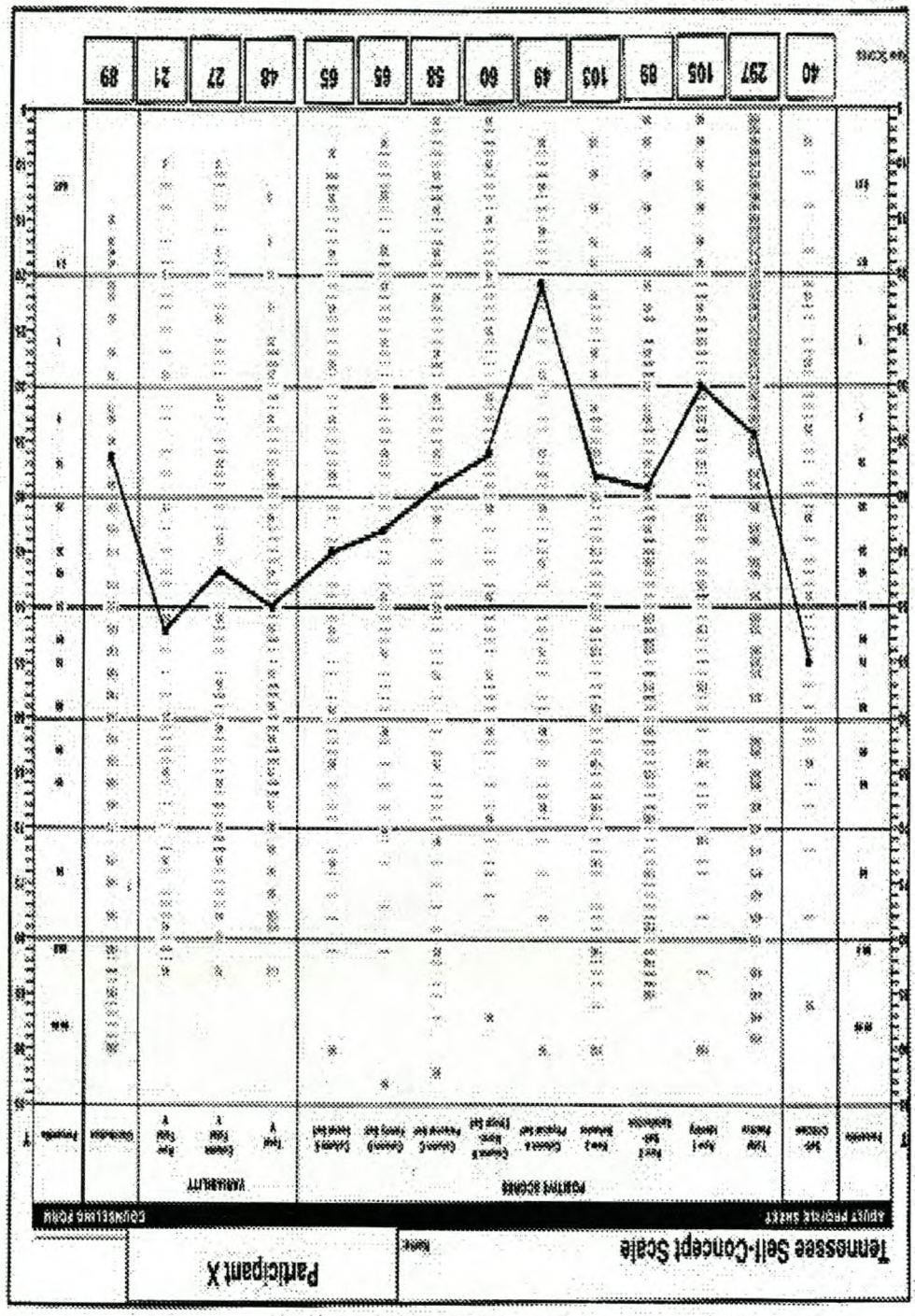
Also, please notice that the **numbers** on each page in the booklet correspond with every second box on the answer sheet. In other words, on the first page, you will answer each question by encircling a number from 1 to 5 in every second box on the answer sheet. If you do have any questions about this, please do not hesitate to ask as you go along. As it may be easy to become confused with the numbers, it may be a good idea to check every now and then that the number of the question in the book corresponds with the number next to your answer on the answer sheet. If you do make a mistake, there is no need to worry. Simply cross out the wrong answer and encircle the right own. Do try to respond to **all** the statements.

Do you have **any questions**?

Fine, then, when you are ready... you can **start** to respond to each of the statements in the booklet by encircling the chosen number on the answer sheet.

Appendix G

The TSCS profile: An example



Appendix H

Introduction to the autobiographical sketch

At the end of our first interview, I introduced and explained the autobiographical sketch:

So we have come to the end of our first interview. Before we meet again for the second interview, I would very much like you to **compose a short autobiographical sketch** for me.

[Present guideline for the autobiographical sketch.]

As a guide, I have stated here **five very broad questions** that you can answer in as much **detail** as possible, again using concrete **examples** wherever you can. This sketch can be hand-written or typed using a type writer or a computer – **whichever way you find the easiest** or with whichever way you feel the most comfortable. You can also choose **how much** you'd like to write about each question. You can, for instance, choose to write half a page about one question, and two about another, or simply one or two or three pages about each question – **the choice is yours**, it is completely up to you.

I will also, as I have indicated there, towards the end, appreciate it if you could **post** the sketch to me as soon as you've completed it, that is, when you have written everything you wanted to, just drop it off in the mail to me. When I **receive** it, I will contact you to **arrange our second interview** at a time that will best suit you.

Perhaps you'd like to take some time now to **read** through the questions... If **any questions** come to mind, please do not hesitate to ask.

Appendix I

Guide to the autobiographical sketch

AUTOBIOGRAPHICAL SKETCH

As in the case of the interviews, your contribution in the form of a short autobiographical sketch is of great value to this study. I would, therefore, truly appreciate it if you could answer the following questions in as much detail as possible, using concrete examples where applicable:

1. **Can you describe the very practical ways in which having ME has influenced and currently influences your life?**

2. **Can you describe how you have experienced those encounters with the medical profession that have concerned ME?**

3. **Can you describe if there has been any changes in the way in which you see and experience yourself since contracting ME, and if there has been any such changes, can you describe it?**

4. **Can you describe your experience of family, friends, co-workers and acquaintances' reactions to and impressions of ME and of you as a ME sufferer?**

5. **Can you describe how you have managed to cope with ME during the entire course of this illness?**

If you have any enquiries concerning the autobiographical sketch, you are very welcome to contact me at the below-stated telephone number or e-mail address.

When the autobiographical sketch has been completed to your satisfaction, I would greatly appreciate it if you could send it to me through the post. I will contact you as soon as I have received it in order to schedule our second interview at a time that will best suit you.

Thank you very, very much!

Ansie Carstens

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